

RESILIENCE AND QUALITY OF LIFE OF FRANCOPHONE PATIENTS LIVING WITH
PROSTATE CANCER: AN ANALYSIS OF THE SITUATION IN NORTHERN ONTARIO,
CANADA.

by

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Abstract

Prostate cancer is the most prevalent cancer among Canadian men with current statistics estimating that one in eight men will develop this disease during his lifetime and for one in 28, it will be fatal (Canadian Cancer Society, 2014). Using social constructivism as its theoretical underpinning, the purpose of the present study was to develop a theoretical framework illustrating how Francophone men from Northeastern Ontario constructed their prostate cancer experiences. More specifically, this study sought to highlight the impact of this disease and the uncertainty it generates on Francophone patients' resilience and overall quality of life by uncovering the strategies they utilized to construct and reconstruct their lives upon receipt of their initial diagnosis, to their selected treatment and subsequently, to their current post-treatment realities.

The central question that guided this inquiry was: *What are the strategies that Northeastern Ontario Francophone men utilize when faced with a diagnosis and subsequent treatment(s) for prostate cancer?* This study was guided by a qualitative social constructivist grounded theory design. To collect data, 22 face-to-face, in-depth interviews were conducted with men from eight different communities throughout Northeastern Ontario. All interviews were digitally audio-recorded using two separate digital audio recorders and were transcribed verbatim in the language of the interview. Data were analyzed using the key principles of grounded theory, mainly, constant comparison, data saturation, as well as initial, focused, and theoretical coding.

Results from this study highlighted the influence of language and culture on the illness experiences of Francophone prostate cancer patients from Northeastern Ontario. In addition, linguistic preferences and geographic locations were shown to be key considerations that weighed heavily within participants' treatment decision-making processes. The role of the wife and the role of the primary family physician were also identified as important supports within the context of men's overall assessment of their cancer experience and the impact of the disease on men's post-treatment quality of life. Using a variety of formal and informal strategies, participants were able to mitigate some of the negative consequences of the disease and demonstrate resiliency in the face of a challenging and uncertain disease.

Overview of Thesis Chapters

This thesis follows a monograph style. The introduction presents the research proposal, the theoretical approach, the conceptual framework, the research question and the hypotheses that guided this study. Chapter 1 presents a critical review of the research literature regarding the development of prostate cancer; the physical, sexual and psychological impact of prostate cancer and the impact of this disease on a person's quality of life. It also provides a summary of the current literature on resilience as well as an overview of the geographical and cultural contexts affecting Francophone prostate cancer patients from Northeastern Ontario. Chapter 2 outlines the theoretical framework and conceptual model guiding this study. Chapter 3 explains the research methodology used. Chapter 4 and Chapter 5 report on the findings of the study while Chapter 6 discusses their theoretical implications. The final chapter of this thesis draws conclusions and discusses the relevance of this study, its limitations, and provides recommendations for future research.

Keywords: prostate cancer, quality of life, resilience, social constructivism.

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INTRODUCTION

For many, the diagnosis of cancer, not the disease but the mere stigma of its presence, can become a death sentence.

(Mukherjee, 2010, p.4)

Prostate cancer is the most prevalent cancer among Canadian men (excluding non-melanoma skin cancer) with current statistics estimating that one in eight men will develop this disease during his lifetime and for one in 28, it will be fatal (Canadian Cancer Society, 2014). In 2014, the Advisory Committee on Cancer Statistics of the Canadian Cancer Society estimated that 23,600 new cases of prostate cancer would be diagnosed in Canada. Incidence rates in Ontario are also staggering with estimates of 9,600 new cases being diagnosed each year (Canadian Cancer Society, 2014).

The rise of prostate cancer incidence is mainly due to the increased aging of the Canadian population (Cancer Quality Council of Ontario, 2013) and in Ontario alone, the number of “older” people, defined as those 65 years and older, is expected to double over the next two decades (Sinha, 2013). Advanced age is a strong predictor of prostate cancer development (Jani, Johnstone, Liauw, Master, & Brawley, 2008). Coupled with a 97% relative survival rate (e.g. 97% of prostate cancer patients survive for five years or more after their initial diagnosis), the impact of prostate cancer on men’s post-treatment quality of life is serious. More specifically, taking into account the potential for this disease to be a long-term chronic condition, prostate cancer is on the verge of becoming a serious financial problem within the core of Canada’s health care system (Canadian Cancer Society, 2012b).

As a widespread but less aggressive cancer, early diagnosis can increase the chances of successful treatment in most cases (Krumwiede & Krumwiede, 2012; Lumen et al., 2012). However, a proactive approach to accessing health care may not be typical. In fact, a 2014 study conducted by Kannan and Veazie (2014) attempted to identify various predictors of avoiding

seeking medical care and the reasons for avoidance behaviour. Based on the analysis of 7,674 observations pulled randomly from the US-based 2007 Health Information National Trends Survey, the researchers sought to understand the reasons why patients delay access to medical services subsequent to self-determination that the symptoms they were experiencing constituted a need for medical attention. Their findings suggested that people avoided accessing health care services for many reasons including a discomfort or distrust of medical doctors, fear or dislike of medical treatments, an unease with having body examinations performed, fear of having a serious illness, and thoughts of dying (Kannan & Veazie, 2014).

While early diagnosis of prostate cancer can lead to more favourable treatment options, it does not guarantee a successful outcome (Lumen et al., 2012). The possible side effects of treatment are substantial and can greatly affect quality of life outcomes (Bergman & Litwin, 2012; Gray et al., 2013; Reeve et al., 2014). For men living with a diagnosis of and treatment for prostate cancer, the process of constructing this experience and assigning meaning to it is highly personal and dependent on the various contexts in which they find themselves (Martin & Peterson, 2009). While ambiguity related to prostate cancer screening, diagnosis, treatment options and long-term side effects is common (Mishel et al., 2009), this uncertainty is often lived in silence because of the dominant ideas of masculinity that may discourage men from seeking health-related services or participating in self-health activities (Addis & Mahalik, 2003; Edwards & Ebrary, 2006). This ambiguity can often lead to poorer health outcomes (Courtenay, 2000). For many, the very term “cancer” instills fear (Lehto, Ojanen, Vakeva, Aromaa, & Kellokumpu-Lehtinen, 2008; Love et al., 2008) and for newly diagnosed men, this fear is most often linked to the potential sexual side effects of treatment for the disease (Millar & Houska, 2007).

As previously mentioned, early diagnosis of prostate cancer can lead to a greater chance of survival, less intensive treatment regimens, and reduce costs to the public health care system (Reeve et al., 2014; Korfage, de Koning, Roobol, Schroder, & Essink-Bot, 2006). However, a proactive approach to health care is not typical with most men (Farrimond, 2012; Jeffries & Grogan, 2012), and as such, being in a position to receive an early diagnosis can sometimes be delayed by their own inaction. In fact, current evidence indicates that men do not generally utilize health care services as often as women (Noone & Stephens, 2008). This under-utilization

is often explained in reference to the influence of the social construction of their masculine identities; whereby the unspoken masculine codes dictate that “real” men are self-reliant, physically fit and uninterested in their health (Farrimond, 2012). One study conducted by Arber and Davidson (2003) suggested that the reason many men are unwilling to turn to health professionals, especially in later life, is that compared with women they are less familiar with the health care delivery system. In other words, this research found that men were less accustomed with accessing health care services such as visiting a doctor while women routinely sought health services throughout their lifetime, for family planning, pregnancy or taking children for immunizations. However, Arber and Davidson (2003) also found that some men recognized *visiting the doctor* as a sign of weakness in and of itself and, as such, they did not want to be seen to be *giving in* to their illness (Arber & Davidson, 2003). Interestingly, a recent study conducted by O'Shaughnessy (2013) concluded that men may exercise health avoidance behaviours without even recognizing the challenges that prostate cancer brings, especially changes to their masculinity (O'Shaughnessy, Ireland, Pelentsov, Thomas, & Esterman, 2013). In other words, a diagnosis of prostate cancer and the implications of treatment for this disease can have a considerable impact on a man's sense of identity by threatening his perception of masculinity and increasing his anxiety levels (Begg & Bach, 2002).

For the Francophone population living in Northeastern Ontario obtaining a diagnosis of prostate cancer can be further exacerbated by several additional factors such as the lack of medical specialists practicing within many Northern communities (thus creating long waiting lists for services, increased burden on technological resources, etc.), geographical issues (such as distance to care, inclement winter weather, poor road conditions, etc.) and communications issues in accessing primary and secondary health services in the language of their choice (Le Réseau francophone de santé du Nord de l'Ontario, 2006). Although Francophones represent a key provincial population group and one of our country's founding peoples, the lack of documented health research relating to this particular population group, especially in northern and rural Ontario, is well documented (Bouchard, Gaboury, Chomienne, Gilbert, & Dubois, 2009; Bouchard, Gilbert, Landry, & Deveau, 2006). In the case of Francophone men who are diagnosed with prostate cancer, dealing with their unique social and geographical contexts while attempting to come to terms with the reality of a diagnosis of a potentially life-threatening

disease can add a level of increased burden for them; one that is worthy of a more detailed investigation.

Situating the Researcher

For several years prior to my decision to return to academia, I had been working at the Northern Ontario School of Medicine with a primary focus on postgraduate medical education. During this time, one of the medical school's affiliate universities began a new Ph.D. program in Rural and Northern Health. This program represented a new option for postgraduate learning in my field of interest and within my home community. My particular focus on cancer research among the Francophone population began when my father-in-law, a non-English speaking Francophone from a very small northern and rural community, was diagnosed with the disease. Witnessing his experience navigating the health care system as a member of a linguistic minority group and seeing the effects of his disease on his quality of life, pushed me to want to study the experiences of other Francophone cancer patients from the North. I became interested in studying prostate cancer specifically because of various collaborative research projects I was involved in with members of a multidisciplinary research group from the Northeast Cancer Research Centre and Laurentian University in Sudbury, Ontario. In addition, studying prostate cancer afforded me a certain degree of separation, since I could never be afflicted with this disease, which I appreciated as a junior researcher. As a bilingual Francophone living in Northern Ontario, I held a particular interest in allowing these men to speak of their experiences in their own voices, and in their own language while also wanting to ensure access to this information to a broader academic community. As I delved further into what I wanted to know about Northeastern Ontario Francophone men's experiences with prostate cancer, I quickly realized that there was a great lack of documented information on this subject, from both the scientific and the academic communities. As a researcher, I wanted to understand the particularities of these men's experiences in order to ascertain what strategies they used as they were faced with a diagnosis of, and subsequent treatment for, prostate cancer. As a female researcher, I pondered whether older men would be willing to open up and discuss their experiences with a disease that touches the core of their health, sexuality and masculinity.

Research Problem

The main focus of this study was to understand the impact of a diagnosis of, and treatment for, prostate cancer on the quality of life of Francophone men living in Northeastern Ontario. Current academic literature demonstrates (Cathomas, 2011; Adami, 2010; Fleshner, 2009; Fradet, Klotz, Trachtenberg, & Zlotta, 2009; Krahn et al., 2009) the existence of a social phenomenon related to the increasing number of men diagnosed with the disease and its influence on their quality of life. Furthermore, the very concept of “quality of life” cannot be determined from a purely objective or positivist viewpoint; it necessitates a deeper understanding and acknowledgement of each person’s definition, perception and interpretation of their own quality of life in relation to their particular disease experience. In other words, how men define their exposure to prostate cancer and its ultimate effect on their quality of life is inevitably a subjective and personal experience which is influenced by several contextual factors that influence this understanding. For example, the circumstances surrounding their health status and quality of life at the time of diagnosis (Bahrami, 2011; Chen, Clark, & Talcott, 2009), their past experience with the health care system (Arredondo et al., 2007; Mols, Coebergh, & van de Poll-Franse, 2007) and the various support networks (personal, financial, social, etc.) available to them during their cancer experience (Badger et al., 2011; Ezer, Chachamovich, Saad, Aprikian, & Souhami, 2012; Manne et al., 2011) can all play a role in how participants view the impact of their disease on their post-treatment quality of life.

There is consensus, however, on the biomedical understanding of this disease as both medical and academic researchers alike acknowledge the fact that prostate cancer is not a natural occurrence within human biology (Loriol, 2013). More specifically, there is agreement that prostate cancer is the presence of abnormal cells within the prostate gland; abnormal referring to cells that exhibit uncontrolled growth and division (Canadian Cancer Society, 2012a). In addition, prostate cancer can also be understood from a theoretical point of view; as a disease that is socially and culturally experienced by a particular group, or individual, in a particular time. As such, how someone interprets their disease experience and its effect on their quality of life can extend far beyond the medical diagnosis and type of treatment they received.

Prostate cancer is a disease that typically presents itself within an aging population. In Ontario, for example, most new cases of prostate cancer are diagnosed in men who are between

the ages 70 and 74 (Cancer Quality Council of Ontario, 2013). For many older men, their lives have been directed by normalized social conventions, whereby prescribed attributes of masculinity such as good health, physical strength and sexual prowess are idealized within the mainstream, culturally-bound understanding of what it means to be a man. Within this subjective context, men faced with a diagnosis of prostate cancer can, therefore, find themselves obliged to deal with a new form a vulnerability that may be entirely foreign to them (Andrew, Mitnitski, Kirkland, & Rockwood, 2012; Charney, 2004; Gannon, Guerro-Blanco, Patel, & Abel, 2010; Jeffries & Grogan, 2012).

It is within this context that I began questioning the impact of prostate cancer on Francophone men's quality of life and particularly, on their individual conceptualizations of its influence. Given the high diagnostic probability and potential cost implications of prostate cancer cases among Ontario's rapidly aging Francophone population and in view of the current lack of formal academic research on how linguistic minority Francophones construct and reconstruct their lives in the face of this disease, the need and importance of this particular study were evident. More so, what was studied and published in relation to men's quality of life after a diagnosis of and treatment for prostate cancer mainly focused on larger quantitative analyses that did not lend themselves to a comprehensive understanding of these individualized experiences.

As a result, it became apparent to me that a social constructivist theoretical framework would be essential in order to bring forward answers to my research question. Recognizing that Francophone prostate cancer patients' subjective experiences (and recounted accounts of the influence of said experiences on their resilience and quality of life) are co-created within a particular contextualized context, a social constructivist framework thus permits us to further explore the concepts of quality of life and resilience within these particular illness encounters. In the following section, readers will be presented the primary research question and hypotheses that initiated this project.

Research Question & Hypotheses

Using social constructivism (Berger & Luckmann, 1966) as its theoretical underpinning, the purpose of the present study was to develop a deeper understanding of the temporal realities and contextual complexities Francophone patients living with prostate cancer experienced. The

main intention of the study was to move beyond the biomedical model of prostate cancer in order to develop a more in-depth theoretical framework illustrating how these Francophone patients experienced the impact of this disease, and the uncertainty it generates, on their overall quality of life (e.g. physical, mental, psychological, social and sexual health) and the resilience they demonstrated during various points throughout their illness experience (e.g., at their time of diagnosis, during treatment and during their post-treatment lives).

In order to gain a thorough understanding of the realities experienced by Francophone patients within the health care delivery model, this study endeavoured to understand the meaning and significance that each participant attributed to his own personal experience with the disease and to better understand the strategies that each participant used in order to reconstruct himself, his relationships and his life as a result of his prostate cancer. As such, this research took into account how participants constructed and reconstructed their realities within a specific social, cultural, linguistic (e.g., one of the two founding population groups of Canada) and geographic context (e.g., Northeastern Ontario: mainly in regions that possess a significant Francophone population; most notably Hearst, Kapuskasing and the city of Greater Sudbury). It also sought to understand how these men, belonging to a linguistic minority group within an often isolated geographic context, described their overall experiences with prostate cancer and its effect on their overall quality of life; from the time of their initial diagnosis to their receipt of treatment and subsequently, to their current post-treatment realities.

The central question that guided this inquiry was: *What are the strategies that Northeastern Ontario Francophone men utilize when faced with a diagnosis and subsequent treatment(s) for prostate cancer?* Along with this global inquiry, three hypotheses were explored. The first hypothesis proposed the idea that due to various cultural (e.g., beliefs, cultural masculine ideals, language, etc.) and geographical (e.g., isolation, distance, etc.) factors, Francophone men delayed their entry into the health services system thus, delaying their time of diagnosis and negatively impacting their overall post-treatment quality of life. The second hypothesis proposed that both language and culture were key factors in understanding how minority Francophones constructed (and reconstructed) their illness experiences. Finally, the third hypothesis suggested that Northeastern Ontario Francophone prostate cancer patients utilized a variety of informal strategies to overcome the barriers they faced within the health care

delivery model and that these strategies helped promote their individual resilience in order to overcome the physical and psychological consequences of their disease management.

This study's primary research question and its underlying hypotheses required me to conduct in-depth face-to-face interviews and analyze and interpret the data following the principles of social constructivist grounded theory methodology. The intent was to highlight the unique temporal realities and contextual complexities of Northeastern Ontario Francophone men's prostate cancer experiences in order to then develop grounded theory that will assist in better understanding the impact of this disease, and the uncertainty it generates in their lives. Results from this study will reveal the limitations of our current health care system as well as the barriers linguistic minority Francophone prostate cancer patients must overcome when faced with a potentially life threatening disease. Results will also demonstrate the various strategies linguistic minority participants employed in order to cope, adapt and/or overcome these barriers while revealing their resilience in the face of a disease that often forced them to redefine their post-treatment realities and quality of life.

This thesis follows a monograph style. The introduction presents the research proposal, the theoretical approach as well as the research question and hypotheses guiding this study. Chapter 1 presents a critical review of the research literature regarding older men and theories of aging; the development of prostate cancer; the physical, sexual and psychological impact of prostate cancer and the impact of this disease on a person's quality of life. It also provides a summary of the geographical and cultural contexts affecting Francophone prostate cancer patients from Northeastern Ontario. Chapter 2 offers the reader a comprehensive overview of the theoretical framework governing this thesis with specific attention paid to the key concepts guiding its implementation. Chapter 3 provides an overview of the qualitative research methodology used in this research. Chapter 4 and Chapter 5 report on the findings of the study while Chapter 6 expands on these results to discuss them within a more contextualized perspective. This study's conclusion discusses implications and recommendations for future research.

Chapter Summary

The introduction of this thesis provided a thorough description of this study's research proposal by contextualizing the landscape in which it occurred. In the following chapter, a review of the various social theories of aging will be provided. In addition, readers will be presented an overview of the development of prostate cancer including information on current national, provincial and regional statistics, screening and detection methods, risk factors and potential treatment options. This chapter will also discuss the impact of the risk and medical uncertainty this disease imposes on patients' overall quality of life as well as the influence of their capacity for resilience when dealing with a diagnosis of, and treatment for, prostate cancer. This chapter will also summarize the current literature on prostate cancer's impact on men's physical, psychological and social quality of life and will expose some of the unique geographical and cultural contexts that can influence prostate cancer patients' constructions of their illness experiences.

CHAPTER 1: LITERATURE REVIEW

A wide variety of literature and resources can, and should, be discussed when examining how Francophone men experience a diagnosis of prostate cancer and more specifically, how this experience influences their resilience and quality of life as they endeavour to reconstruct their world in the face of this disease. In the following pages, a comprehensive review of the literature surrounding older men's health, the development of prostate cancer and its potential impact on men's physical, social, and psychological quality of life will be provided. Specific attention will be given to the impact of risk and medical uncertainty on patients' resilience and quality of life when diagnosed with a potentially life-threatening disease. Finally, this chapter will expose some of the unique geographical and cultural contexts that can influence prostate cancer patients' constructions of their illness experiences.

1.1 Men and Social Theories of Aging

Prostate cancer is known to be an older-man's disease; linked to the very core of the male identity (Arrington, 2008). Central to any study related to the impact of this disease on older prostate cancer patients and their self-perceived quality of life is the identification of certain disease-related factors that are often considered to be part of the normal aging process. As such, a more comprehensive review of the current literature theorizing older men's health is useful in facilitating a deeper understanding of context surrounding older men's experiences with potentially long-term, chronic conditions.

The theoretical life stages model developed by Erik Erikson (1959) and the psychosocial life stage theory proposed by Levinson and colleagues (1978) provided a foundation from which subsequent theories of aging have emerged. A closer look at both of these models will contextualize the framework of this present study. Erikson's (1959) most notable contribution to the academia of human development was his conceptualization of the "Eight Ages of Man"; the eight successive life stages he believed each person was required to complete in order to reach their full development. *Middle adulthood* (35 to 55-65 years of age), represented the seventh age along his theoretical developmental continuum. In this stage, the primary concern of the middle adult revolved around issues of *generativity*, which he defined as the preservation and

transmittance of one's culture and values to the next generation. In the final stage of his development model, the *late adulthood* stage (55-65 years of age until death), people were thought to confront a crisis of integrity versus despair; whereby the older adult either feels a sense of contentment and happiness in regards to his or her life contributions and meaning (integrity) or a sense of anguish over the lack of purpose or significance of their life (despair) (Erikson, 1959). Like Erikson, Levinson and colleagues (1978) believed that a human being's life evolved in a relatively sequential order of developmental periods that were accentuated by transitional periods, which could last for several years between each stage. According to their research, a person who transitioned into late adulthood was likely to be consumed by personal and social responses to their bodily decline, with an accented awareness of their own inevitable mortality (Levinson, 1978).

More recently, other theories of aging (e.g., role theory, activity theory, symbolic interactionism) have emerged to help further define an understanding of aging as the extremely complex, multifactorial process it is (Bengtson, 2009; Burbank, 1986). Under the umbrella of what is now commonly called "social gerontology," many of these theories highlight important nuances related to older men, their health and their quality of life. In the following sections, a brief overview of these various theories of aging will be presented.

Role Theory is based on the premise that the process of aging perpetuates adjustment issues due to the relinquishment of social relationships and dominant roles typical of adulthood in later life (Lynott & Lynott, 1996). In other words, changes to socially and culturally established roles can pose a particular quandary for older adults in the sense that they are more likely to lose their societal roles than to acquire additional roles in later life. This in turn may cause them to experience a loss of identity and esteem (Tannenbaum & Frank, 2011; Martin & Peterson, 2009; Noone & Stephens, 2008). For example, men who experience such changes, especially those related to their dominant roles of masculinity, can be further challenged with contradictions in their accustomed social standing within many paternalistic societies when age-related factors, such as illness, are the primary cause of these deemed "premature" position changes.

Activity Theory, initially presented by Havinghurst and Albrecht (1953) and later conceptually clarified by Lemon and colleagues (1972), is often referred to as “the implicit theory of aging” and postulates that although aging individuals face inevitable changes related to their physical functioning and health status, their psychological and social needs remain essentially the same. As such, forced decreases in customary levels of activity can lead to a diminished sense of well-being. This is especially relevant for men facing the consequences of treatment for prostate cancer, who may continue to have the drive to want to pursue physical activities yet no longer possess the corporal ability to perform them.

Several other theories of aging have moved beyond the personal standpoint and instead have recognized the influence of broader social parameters on aging adults’ experiences. For example, Cumming and Henry’s (1961) *Disengagement Theory*, in contrast to the role theory and activity theory, shifted thinking about aging away from the individual to the social system as a source of explanation. From this theoretical standpoint, it is argued that as age increases, older adults naturally become less involved with social institutions and that this gradual disengagement is useful within society, which would otherwise be faced with even more disruption by sudden withdrawal of its members (Cumming & Henry, 1961). *Continuity Theory* also allowed for a certain degree of role loss, a decline in physical activity and an increase of social disengagement while asserting that older adults undertook adaptive strategies and made adaptive choices in an attempt to maintain or preserve links with their own past experiences (Onega & Tripp-Reimer, 1997). *Socioenvironmental Theory*, another macro theory of aging, attempted to understand the influence of the social and physical environment on the activity choices of aged individuals and found that older people responded to the social significance of occasions rather than to some absolute aspect of said events (Nimrod & Kleiber, 2007). Finally, the *Exchange Theory of Aging* held that the older adult population possessed less power in relation to younger people because these aging adults possessed fewer resources and as such, continued interaction with younger adults would become more and more costly to them (Ungar, 2011).

While many of the above-presented theories of aging continue to show some relevance in today’s academic literature, one particular framework known as *Symbolic Interactionism*, has demonstrated itself to be even more relevant within a socially constructed understanding of any given phenomenon. According to Herbert Blumer (1969), *Symbolic Interactionism* is a theory

that holds the belief that people, including older adults, behave toward objects, including other people, according to perceptions and meanings developed through social interactions. In other words, Symbolic Interactionists view individuals as conscious actors in the world who adapt to situations and events on the basis of the perceptions and meanings they have constructed for these particular situations and events (Blumer, 1969). Symbolic Interactionists, therefore, view aging and its experiences as socially constructed and strive to uncover how aging adults view and assign meaning to their experiences of old age within their particular social and cultural contexts.

Theoretical frameworks, such as those presented above, offer a variety of lenses through which the experiences of older men can be better conceptualized, understood and interpreted. These forms of analytical models allow the researcher to better grasp the complexities of issues that older men may face, especially when they are confronted with a life-threatening disease such as prostate cancer.

1.2 The Development of Prostate Cancer

According to the World Health Organization (1948), health refers to an overall state of physical, mental and social well-being and not merely the absence of disease or infirmity. However, among an aging male population health is often self-described as the absence of any reason to need to access health services. Thus, the absence of symptoms is often considered indicative of good health among men in later life (Tannenbaum & Frank, 2011). In the following sections, an outline of current statistics and risk factors for prostate cancer, biomedical factors associated with the disease, screening and detection methods as well as current treatment options will be presented.

1.2.1 Prostate Cancer Statistics

Current statistics indicate that each day, 65 Canadian men are diagnosed with prostate cancer and for 11 men daily, it is fatal (Canadian Cancer Society, 2014). Shockingly, prostate cancer represents 27% of all male cancer cases and 10% of all male cancer deaths in Canada (Canadian Cancer Society, 2014). Although the mortality rates related to prostate cancer have declined since the early 1990's, this decline is primarily attributed to medical interventions that promote earlier diagnosis times and to the fact that many tumours have a slow growth rate

(Canadian Cancer Society, 2012a). While it has been suggested that prostate cancer has reached epidemic proportions for older men (Fradet et al., 2009; Jani et al., 2008), it is often positioned as a long-term chronic disease that men die with, rather than die from (Mishel et al., 2009). Without a known cause or cure, the number of men diagnosed will continue to increase with Canada's aging population and will remain a growing financial burden for the Canadian health care system (Ellison & Wilkins, 2009; Remzi & Djavan, 2004).

As previously mentioned, but worth highlighting again, prostate cancer is the most prevalent cancer among Canadian men (excluding non-melanoma skin cancer) with a weekly average of 453 men diagnosed and 77 men killed by this disease (Canadian Cancer Society, 2014). According to the 2007 Ontario Cancer Registry, which was the most recent year in which the Registry was able to report complete data at the time of this study, there were 9,678 new prostate cancer cases in Ontario alone and of these, 24% were from men living in Northeastern Ontario¹ (Canadian Cancer Society, 2012b; Cancer Care Ontario, 2012).

1.2.2 Risk Factors for Prostate Cancer

Older age (Jani et al., 2008) and a positive family history of prostate cancer (Brandt, Sundquist, & Hemminki, 2012) appear to increase the risk of developing this disease. Although prostate cancer is most commonly diagnosed in men aged 65 years and older, the incidence begins to rise at age 50 (Canadian Cancer Society, 2012c). Heredity may also play a role in some types of prostate cancers (Chen, Page, Chen, & Giovannucci, 2008; Filion, Taussky, Bahary, & Maugard, 2007) as men with a family history of the disease are seen to have a higher risk of developing prostate cancer. Current research suggests that having one family member with prostate cancer doubles a man's own risk and having three family members afflicted with the disease increases his risk by eleven-fold (Johanneson et al., 2010).

The study of familial clustering among particular cultural groups is also starting to gain momentum within the current academic literature. For example, Filion and colleagues (2007) examined the frequency of familial clustering in a French-Canadian population of prostate cancer

¹ Northern Ontario is defined as the geographic catchment area of the Northeastern Local Health Integration Network (LHIN) including but not limited to all communities included within the present study. For a map of LHINs, please visit http://www.lhin.on.ca/FindYourLHIN.aspx?ekmense1=e2f22c9a_72_254_btnlink

cases and found a higher percent of French-Canadian men with at least 1 first-degree relative with prostate cancer than what was previously reported for an unselected population in Canada (25.1% vs. 14.7%, $p < .0001$) (Filion et al., 2007).

Familial clustering was also studied by Albright and his collaborators (2012) who reported significant evidence demonstrating a heritable contribution to various cancer predispositions, including prostate cancer. Findings from this research indicated evidence that extended beyond a genetic predisposition to disease to also include an environmental proximity component; which they hypothesized would contribute to similarities in the cluster population's lifestyle choices (Albright et al., 2012).

Lifestyle choices are important to consider when studying prostate cancer since obesity (Presti, 2005), physical inactivity (Darlington, Kreiger, Lightfoot, Purdham, & Sass-Kortsak, 2007), eating a diet high in fat (Discacciati & Wolk, 2014), occupation (Sass-Kortsak, Purdham, Kreiger, Darlington, & Lightfoot, 2007) and cadmium exposure (Ferris-I-Tortajada et al., 2011; Julin et al., 2012) are often cited as other possible risk factors for the disease. Male hormones (e.g., androgens), particularly testosterone, may also play a role in the development of the disease (Grossmann & Wittert, 2012).

Within an aging population, prostate cancer has become a major medical and socioeconomic problem (Adami, 2010). As an often long-term chronic disease, the health care costs associated with prostate cancer increasingly add to Canada's already burdened and fiscally-challenged health care system. A research study conducted by Krahn and colleagues (2009) estimated the total health care costs and costs attributable to prostate cancer across all stages of the disease for 42,484 men diagnosed with prostate cancer in Ontario (1995-2002), and demonstrated that health care costs are highest around two events: cancer diagnosis and cancer death. Findings from this study established that total direct costs per person per 100 days (in Canadian dollars, 2004) were: \$1,297 during the 6-month period before diagnosis; \$3,289 during the twelve-month period after diagnosis; \$1,495 during the continuing care phase; \$5,629 during patients' pre-terminal phase (from 18 to 6 months before death); and \$16,020 during men's terminal care period (6 months before death) (Krahn et al., 2009). Furthermore, results from this study showed that prostate cancer-related costs accounted for 72% of total costs in the 12-month

period after diagnosis and concluded that advanced stage at diagnosis, being older at diagnosis and having higher comorbidity were associated with these increased costs. As a widespread but less aggressive cancer, early diagnosis of prostate cancer not only increases the chances of successful treatment in most cases, it can assist in reducing the overall financial burden on both Canada's health care system as a whole and individually on each patient by minimizing their out-of-pocket private payer expenses (e.g., lost work days, travel days to treatment centres, etc.).

1.2.3 Stage, Grade and Symptoms of Prostate Cancer

The word prostate is derived from Greek words meaning *one who stands before* (Phillips, 1994). The prostate gland was named as such because it is a male sex gland that stands before the bladder. Located in front of the rectum at the lower part of the intestine (just below the bladder, a standard prostate gland has a pyramidal shape (about the size of a walnut) and surrounds the urethra. The prostate's main physiological function is to assist in reproduction by making part of the seminal fluid that mixes with sperm from the testicles to make semen.

Prostate cancer begins when something triggers an abnormal growth in the cells of the prostate gland. Most prostate cancers begin in the peripheral zone and compared to other forms of cancer; prostate tumours are very slow growing (Jamnicky & Nam, 2008); resulting in many patients being asymptomatic at the time of their initial diagnosis (Bryant & Hamdy, 2008).

Prostate cancer can be detected at any stage of its development. *Staging* refers to the size of the tumour and indicates whether it has spread beyond the place where it originated. Table 1 (below) identifies the four main stages of prostate cancer recognized by the Canadian Cancer Society (2014):

Table 1

Prostate Cancer Stages

Stage	Description
1	Cancer is found in the prostate only.
2	Cancer is larger than stage 1, but is still found only in the prostate.
3	Cancer has spread outside the prostate, but not to nearby organs.
4	Cancer has spread to nearby organs, lymph nodes or distant parts of the body.

Source: Canadian Cancer Society (2014)

Early-stage prostate cancer generally does not cause any noticeable symptoms because it occurs in the outer layer of the prostate gland and typically does not interfere with urination (Jamnicky & Nam, 2008). However, in later stages of localized or metastasized prostate cancer, men can experience symptoms such as waking up several times during the night to urinate; pain or difficulty with urination, presence of blood in the urine, increased pain or stiffness in the lower back, upper thighs or hips, bone pain, weight loss or swelling in legs and feet (Canadian Cancer Society, 2014).

Another widely accepted indicator of the potential of prostate cancer to grow and spread is the Gleason Staging System. Introduced in 1966 after pathologist Dr. Donald Gleason, the Gleason Staging System grades tumour samples according to their level of deviation from normal cell architecture (Gleason, Mellinger and Veterans Administration Cooperative Urological Research Group, 2002). Grades are assigned to each of the two largest areas of cancer in the tissue samples and range from 1 to 5, with 1 being the least aggressive and 5 the most aggressive. These two scores are then added together, with the larger component presented first, to produce a Gleason score. The following chart presented by the Canadian Cancer Society (2014) provides a description of each grade with its corresponding Gleason score range:

Table 2

Prostate Cancer Grade and Gleason Score

Grade	Gleason score	Description
1	2–4	Low grade – slow growing, less likely to spread
2	5–7	Moderate grade – grows slightly faster than grade 1 and may spread
3	8–10	High grade – tends to grow quickly, more likely to spread

Source: Canadian Cancer Society (2014)

Many men with a low grade on the Gleason Staging System are also frequently asymptomatic (Bryant & Hamdy, 2008). If symptoms are present, they are often confused with other health conditions or are mistaken for the usual signs of aging (McKenna, 1994). The usual warning signs include changes in bladder habits (the increased need and urgency to urinate, difficulty in starting or stopping the urine flow, inability to urinate, burning or pain during urination, etc.), hematuria (presence of blood in the urine), and painful ejaculation (Canadian Cancer Society, 2012a). Symptoms of later stages of prostate cancer can include continuing pain in the lower back, pelvis, and upper thighs, lymphedema (localized fluid retention and tissue swelling caused by a compromised lymphatic system), impotence (inability to develop or maintain an erection) or less rigid erections of the penis, anemia (is a decrease in number of red blood cells in the blood), loss of appetite, and weight loss (Canadian Cancer Society, 2012a).

1.2.4 Methods for Detecting Prostate Cancer

Methodologies used to identify and stage prostate cancer include physical examinations (e.g., personal and family medical history), a digital rectal exam, laboratory tests including the prostate specific antigen test, blood tests and urine tests; imaging (e.g., transrectal ultrasound); needle biopsy; and cystoscopy (e.g., endoscopy of the urinary bladder via the urethra), in addition to medical tests such as x-rays, ultrasounds and scans (Ilic et al., 2013).

In November 2014, the Canadian Task Force on Preventive Health Care, endorsed by the College of Family Physicians of Canada, released revised clinical practice guidelines which

formally recommended against prostate cancer screening in the form of prostate specific antigen (PSA) testing (Bell et al., 2014). According to their position, the available evidence does not conclusively demonstrate that prostate specific antigen screening reduced prostate cancer mortality. In fact, their review of published evidence based research determined that screening for the disease represented an increased risk of physical and psychological harm for patients related to the high incidence of false-positive results, the potential harms of biopsies (e.g. hematuria, infection, hospital admission and death), and consequences of over diagnosis (Bell et al., 2014).

The Task Force's revised guidelines are in direct contrast with the views of Prostate Cancer Canada (PCC), a national research and awareness foundation, which continues to lobby for prostate cancer screening by advocating their own screening guidelines that stipulate that: 1) Men should get a PSA test in their 40s to establish their baseline; 2) Men at high risk for prostate cancer should talk to their primary care provider before age 40 about prostate cancer; and 3) At or over age 70, the decision to end PSA testing should be based on individual factors (Prostate Cancer Canada, 2014).

This medical debate is fuelled by the lack of evidence whether the benefits of screening for prostate cancer outweigh the potential risks involved, and there is no conclusive proof that screening of asymptomatic men reduces mortality from the disease (Public Health Agency of Canada, 2009). Also, since the prostate specific antigen blood test lacks sensitivity and cannot distinguish between clinically significant tumours and those that are slow-growing and unlikely to progress during the patient's lifetime, men who return a positive prostate specific antigen result may face further intrusive testing and treatment-related consequences that could have a considerable impact on their quality of life (Junod, 2007).

While a prostate specific antigen screening test is not intended to have a diagnostic end but to increase the chances of cure, there appears to be much confusion surrounding its usage within the current service delivery model (D'Amico & Smith, 2012). In a 2009 study on older men's reactions to the medical debate surrounding the use of the prostate specific antigen test for prostate cancer screening, Dixon and colleagues (2009) found that men had a somewhat limited understanding of the concept of screening and tended to think of it in the same way as diagnostic

tests, rather than considering screening as a routine preventive health management strategy (Dixon, Scully, Wakefield, & Murphy, 2009). In light of these findings, and given that many Francophone men in Northeastern Ontario may not have access to health services in their language of preference, there is the potential for an even greater sense of confusion among them regarding screening methods for this disease.

1.2.5 Risk-Adapted Treatment Options

A variety of treatment options are available to men with prostate cancer. The risk category a man falls under most often determines his choices for treatment. The D'Amico Classification System (D'Amico & Smith, 2012; D'Amico et al., 1998) presented below, is the most common assessment tool urologists use in determining patients' risk assessments. This system combines findings from men's prostate specific antigen test; digital rectal exam and Gleason score in order to determine their risk of disease progression.

Table 3

D'Amico Classification System

	Low Risk	Intermediate Risk	High Risk
Prostate specific antigen	<10 ng/mL	10 - 20 ng/mL	>20 ng/mL
Tumour (T) stage	T1c-T2a	T2b-c	T3
Gleason score	<6	7	8-10

Source: D'Amico & Smith, 2012; D'Amico et al. 1998

Treatment options are based upon the stage or extent of the prostate cancer, as well as in consideration of the patient's age and potential life expectancy, and his associated comorbidities (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012). Low-risk patients (e.g., men who are found to have low-grade or localized prostate cancer) are often most suitable for active surveillance or watchful waiting. This involves regular and ongoing monitoring of the prostate specific antigen blood test results and the results of the digital rectal exam as well as

repeat prostate biopsies at regular intervals. Men determined to have an intermediate risk of disease progression are usually required to undergo standard intervention procedures such as a radical prostatectomy (e.g., surgical removal of the prostate gland), brachytherapy (e.g., implanting radioactive seeds directly into the prostate gland) or external beam radiation (e.g., where an external source of radiation is directed at the tumour from outside the body). In addition, certain Canadian cities are offering cryoablation (e.g., freezing) and high-intensity focused ultrasound (e.g., heating) treatments, although these are still considered experimental in nature (Barkin, 2011; Chin, Al-Zahrani, Autran-Gomez, Williams, & Bauman, 2012; Donnelly et al., 2010).

For high-risk patients, treatment options are often evolving and can involve more than one type of therapy. Traditionally, men with metastatic disease have typically been treated with external beam radiation and hormonal therapy. These treatments can take place for up to three years. In particular cases, chemotherapy may also be used to limit any further metastases and physical complications (Canadian Cancer Society's Steering Committee on Cancer Statistics, May 2012). Patients who have advanced disease progression and are unable to undergo radiation or surgery may be treated with androgen deprivation therapy, a treatment that turns off the body's ability to produce testosterone by means of hormonal drugs or removal of the testicles (Chipperfield et al., 2013).

The decision whether or not to undergo treatment is not always straightforward given the potential negative side effects of prostate cancer treatments (Begg & Bach, 2002). Currently, there is no medical or scientific consensus regarding the most appropriate treatment option to enhance survival rate of men with prostate cancer (Eton & Lepore, 2002). Unfortunately, each treatment can produce a wide range of short-term side effects (e.g., increased stress, hot flashes, loss of desire for sex, weight gain, etc.) and long-term or permanent side effects (e.g., incontinence, impotence and infertility) (Canadian Cancer Society, 2014). In the absence of medical consensus on how to best treat prostate cancer, most prostate cancer patients base their treatment decisions on their assessment of the perceived risks to their quality life associated with each potential treatment choice.

In the following sections, a closer review of current literature on the various physical, psychological and social implications of the management of this disease will be examined within the context of patients' uncertainty, their assessments of the perceived risk of their treatment decisions and their capacity for resilience.

1.3 The Impact of Prostate Cancer

A diagnosis of prostate cancer occurs within the context of medical uncertainty that is unparalleled by other forms of cancer (Mishel et al., 2009). Current screening and detection methods for prostate cancer have led to an increase in early stage diagnoses (Ilic, Neuberger, Djulbegovic, & Dahm, 2013). In fact, many men are asymptomatic and both physically and sexually active at the time of their initial diagnosis. As such, numerous patients are being treated by curative procedures and are undergoing disease management protocols for longer periods of time (Prezioso, Galasso, Di Martino, & Iapicca, 2007). For many men diagnosed with prostate cancer, maintenance of their quality of life may be just as important as survival, and as such, quality of life considerations may be central in their treatment decision-making process.

Quality of life is a multidimensional construct consisting of physical, psychological, and social dimensions (Ferrans, Zerwic, Wilbur, & Larson, 2005). While there currently exists a lack of definitional consensus within contemporary health care literature (Milton, 2013), several authors recognize quality of life as a multidimensional construct that can be conceptualized in terms of one's normal functioning, general well-being, social usefulness, ability to fulfill their life's goals, overall happiness and life satisfaction (Davies, Kinman, Thomas, & Bailey, 2008; Ferrans et al., 2005; Harden et al., 2013; Wilson & Cleary, 1995). Economic stability (Chang et al., 2012), psychosocial well-being (Ezer et al., 2012), spiritual connectedness (Hamrick & Diefenbach, 2006; Zavala, Maliski, Kwan, Fink, & Litwin, 2009) and family dimensions (Badger et al., 2011; Turner et al., 2013) also are frequently incorporated into conceptualizations of quality of life. Given increasing survival rates of men diagnosed with prostate cancer, quality of life is an important aspect of any study on the effects of various treatment options for the disease (Altwein et al., 1997).

While there is no agreement among specialists regarding the *right way* to treat prostate cancer, research suggests that men are more likely to live longer with treatment than without, but

usually at the expense of their quality of life (Chen et al., 2009; Halbert et al., 2010; Litwin, 2009). Although significant advances have been made in the treatment of prostate cancer, the general rule remains that the individual selection of therapeutic treatments is most often dependent upon the age of the patient, their general health status and their personal preferences (Brzozowska et al., 2012). While widespread interest in understanding patient-centered quality of life outcomes has led to the development of various measurements (e.g. questionnaires) to evaluate the impact of the disease on patients' quality of life, consensus remains that the treatment of prostate cancer extends across the cancer control continuum and encompasses both short- and long-term treatment-related side effects to patients' physical, psychological and social well-being. In other words, although quantitative questionnaires provide researchers with a general idea of the situation of the population they are studying, they do not capture the particularities that exist within any particular group; such as linguistic minority Francophones living in Northeastern Ontario. Recognizing the particularities and significance attributed to patients' unique circumstances is imperative for a comprehensive understanding of the impact of this disease on their lives.

1.3.1 Risk, Uncertainty & Resilience

The study of patients' risk assessments in relation to their treatment decisions has gained increased momentum in North America within various areas of research including environmental sociology, disaster research, social work, health research, crime prevention research and political organization and regulation (Beck, 1999). Within the social sciences, the study of risk has been primarily captured within the cultural theory (Douglas, 1992) and the systems theory (Luhmann, 2005); whereby the focus of risk departs from the objectivist view in favour of a more subjective, contextualized understanding of its development (Adam, Beck, & van Loon, 2000).

More specifically, many social researchers recognize that an assessment of risk is both individually created and socially formed; based upon the perceptions, values, meanings and inherent beliefs attributed to its development (Le Breton, 1995). Luhmann (2005), for example, referred to risk as the form in which the future decisions are made visible and rationalized; whereby risk is understood as a result of actions that were neither necessary nor impossible but contingent and dependent upon human action. In other words, Luhmann (2005) asserted that risk is socially produced rather than naturally determined and as such, in order to fully appreciate an

individual's assessment of risk, one must contextualize this assessment within the parameters of the individual's social, historical and cultural background. Consequently, it is important to understand risk as a social construction within a particular setting; not as an absolute, but rather as local, individualized and particular.

Within prostate cancer patients' illness experiences, there is an inherent acknowledgement of the influence of illness uncertainty on patient's perceived risk. In fact, many newly diagnosed prostate cancer patients live with the uncertainty of which treatment is best given their particular circumstances (Clark & Talcott, 2006). Several authors have commented on the impact of risk assessment on prostate cancer patients' treatment decision-making process, (Hamilton et al., 2013; Kazer et al., 2013; Moreau et al., 2012) treatment satisfaction (Hart et al., 2008; Jayadevappa et al., 2009) and post-treatment quality of life (Clark & Talcott, 2006; Miller, 2013).

The influence of illness uncertainty on prostate cancer patients' perceived risk was originally described using the conceptual framework proposed by Mishel (1981). According to Mishel and colleagues (1981, 1988), there are four main types of illness uncertainty: 1) the uncertainty regarding illness state; 2) the complexity of treatment and the larger care system; 3) the lack of information about diagnosis and illness severity, and 4) the uncertainty about prognosis and disease course. According to the authors, each form of uncertainty offered an increased opportunity for greater self-determination of risk. This belief is supported within recent studies examining the importance of uncertainty among prostate cancer survivors by suggesting that the impact of uncertainty on a cancer survivor's health state is often mediated by their appraisal of danger (Bailey, Wallace, & Mishel, 2007; Mishel, 2009; Wallace, 2003). For example, one study by Germino and collaborators (1998) evaluated the role of uncertainty in determining the quality of life in men with localized prostate cancer and their families by comparing baseline demographics, measurement of uncertainty, and quality of life outcomes among 140 men who underwent surgery, 35 men who were treated by external beam radiation therapy and 26 men who chose active surveillance. After controlling for age and education, results from this study found no differences in the levels of uncertainty among the different treatment groups, yet demonstrated marked differences in uncertainty related to race and social

environment; whereby worsening social functioning was associated with increasing uncertainty (Germino et al., 1998).

Another large randomized clinical trial also conducted by Mishel and colleagues (2009) assessed an intervention to counter uncertainty in men with both localized disease and advanced prostate cancer and documented the adverse effects of illness uncertainty on their quality of life. Results from this study supported the importance of *uncertainty management* (e.g. cancer knowledge, problem-solving, and patient–provider communication), medical communication competence, number and helpfulness of resources for information as well as the impact of decisional regret. The authors concluded their study by emphasizing the potential benefit of targeted intervention strategies for men facing a diagnosis of prostate cancer (Mishel et al., 2009).

Inherently, patients’ cultural beliefs and practices influences how they interpret risk, resilience and quality of life (Surbone, 2008). As such, their perceptions (or misperceptions) of their disease, their access to primary and secondary health services, and their relationship to individual physicians are important considerations when attempting to gain a deeper insight into how they come to understand their post-cancer realities (Surbone, 2008). Undeniably within prostate cancer health research, men who are diagnosed with prostate cancer are faced with decisions that both determine their comfort with risk and their capacity for resilience in the face of a potentially life-threatening disease.

In the last decade, a growing body of research on resilience has emerged across social science and health disciplines (Bottrell, 2009; Denz-Penhey & Murdoch, 2008; Didkowsky, Ungar, & Liebenberg, 2010; Luthar, 2003; Rutter, 2012; Ungar, Ghazinour, & Richter, 2013; Ungar, Liebenberg, Dudding, Armstrong, & Van de Vijver, 2013). Foundational work on the concept of resilience initially arose within the field of developmental psychopathology in the 1970’s (Garmezy, 1971). Resilience is understood as a dynamic developmental process that involves many influences. While conceptual interest in resilience permeates several domains of research within the social sciences, there is little consensus about the definition and meaning of this concept (Rutter, 2012; Ungar, 2012). However, within the myriad of interpretations of the term resilience, two dominant themes of influence appear to exist within the current

understanding of this concept. The first asserts that within an individual's responses to a stressful event, the concept of resilience focuses on recovery (Ungar et al., 2013). Within this understanding, recovery refers to an individual's ability to rebound from a particular stressor, such as prostate cancer, a capacity to regain equilibrium and to return to an initial sense of health (Reich, Zautra, & Hall, 2010). The second and equally important thematic dimension of resilience relates to the concept of sustainability. This refers to an individual's ability to maintain the recovery trajectory over time, and for some, this includes a dimension of improved function or increased well-being as a result of healthy reactions to a stressful event (Reich et al., 2010).

As with any chronic illness, prostate cancer is a source of stress that demands major adjustments for patients and their families. While previous conceptions of the experience of cancer were studied within a biomedical model of physiological disease (Bryant & Hamdy, 2008), increased observations of cancer patients' abilities to recover and even grow from the cancer experiences has led researchers to move away from the dominant disease model towards a more contextualized understanding of resilience that accounted for larger socially constructed influencers that impacted a patient's ability to overcome such a stressful event (Ungar, 2012; Ungar et al., 2013).

For example, a recent study by Sharpley and colleagues (2014) investigated the protective effect of psychological resilience against anxiety and depression in a prostate cancer patient population. Surveys, background data and resilience scales were collected from 425 prostate cancer patients and results demonstrated that patients' self-identified resilience scores were a significant buffer against their depression scores. In other words, participants who demonstrated higher levels of resilience tended to also display lower depression scores. The authors concluded that measures of resilience could be useful in screening depression in at-risk prostate cancer patients noting that these patients could also benefit from resilience training to enhance their ability to cope effectively with the stress of their diagnosis and treatment (Sharpley, Bitsika, Wootten, & Christie, 2014).

1.3.2 The Physical Impact of Prostate Cancer

Men diagnosed with localized prostate cancer can choose from multiple treatment regimens. As previously described, these treatment decisions are often made within a context of

medical uncertainty and are often made in view of the patient's assessment of the potential risk of treatment decisions on their quality of life. For many, physical quality of life complications are often given the most consideration (Davison, So, & Goldenberg, 2007; O'Rourke, 2007; Prezioso, Galasso, Di Martino, & Iapicca, 2007).

For example, radical prostatectomy procedures, which are frequently performed in patients with clinically localized or non-metastatic prostate cancer, entail the surgical removal of the prostate gland and often its surrounding areas. This radical procedure can result in immediate adverse side effects associated with, but not limited to, prostatectomy procedural accidents (e.g. injury to the rectum could require the use of a temporary colostomy), recovery complications, short-term constipation, incontinence, erectile dysfunction, infertility, long-term side effects, and as with any major surgery, there is a slight risk of death (Kimura et al., 2013; Resnick et al., 2014; Van den Bergh et al., 2014).

Current literature often cites side effects related to sexual dysfunction and/or sexual bother as most common fear or regret that men have following surgery for prostate cancer (Chung & Brock, 2013; Ferrer et al., 2013; van den Bergh et al., 2014). Sexual function relates to patients' symptoms severity (current and prior to their cancer diagnosis) and most often refers to changes in libido, erection function, orgasm, frequency of sexual intercourse and sexual activity (Szymanski, Wei, Dunn, & Sanda, 2010; Wei, Dunn, Litwin, Sandler, & Sanda, 2000). Sexual bother, on the other hand, refers to the degree to which patients consider their sexual side effects to be problematic (Wei et al., 2000). Multifactorial in nature, sexual bother consists of both physiological and psychological elements and is influenced by a multitude of factors related to sexuality such as men's expectations for sexual performance, their perceptions of a diminished masculinity, their having an available sexual partner, and one's partner's sexual function and interest (Benedict et al., 2014; Kimura et al., 2013).

As previously mentioned, sexual function and/or sexual bother are common fears men have when undergoing treatment for prostate cancer. For example, a 2008 study conducted by Namiki and colleagues (2008) reported significant deterioration in sexual function, incontinence, and hardship scores (which score perceived hardship due to cancer) among patients immediately after radical prostatectomy, with scores diminishing over time. By two years post-operative, 57%

and 81% of their subjects had fully recovered to baseline urinary function and bother, respectively (Namiki et al., 2008). Mean recovery time to baseline urinary function and bother was 8.3 months and 4.7 months, respectively. Only 25% of patients returned to the baseline sexual function level while 83% had reached baseline sexual bother. Among those participants returning to their own baseline scores, the mean recovery time was 10.9 months for sexual function and 5.3 months for sexual bother (Namiki et al., 2008).

In another study, Brajtbord and colleagues (2014) studied the impact of age on sexual and urinary function and bother during the first two years post-radical prostatectomy. Among the 1,806 patients examined, younger men reported higher sexual function scores at each time point and higher rates of sexual function decline at one year than older men (81% versus 75%, $p < .01$). Younger men also had higher sexual bother decline rates at one year (74% versus 61%, $p < .01$) and two years (62% versus 56%, $p = .02$) after radical prostatectomy. In multivariate analysis, age was associated with changes in sexual function and sexual bother from baseline through two years, both $p < .01$. The concluding results demonstrated that younger men reported higher sexual function and urinary function overall and experienced greater declines in sexual bother (Brajtbord, Punnen, Cowan, Welty, & Carroll, 2014).

Stanford and colleagues (2000) also conducted a study with the purpose of measuring changes in urinary and sexual function in men who underwent radical prostatectomy surgery for clinically localized prostate cancer (Stanford et al., 2000). To undertake this study, results from the Prostate Cancer Outcomes Study, which compiled longitudinal assessments of functional status in a large community-based cohort of patients with localized prostate cancer treated with radical prostatectomy surgery, were analyzed. Participants within this study included a total of 1,291 black, white and Hispanic men between the ages of 37 and 79 who were diagnosed with prostate cancer between October 1, 1994, and October 30, 1995, and underwent a radical prostatectomy within six months of their diagnosis of clinically localized prostate cancer. Urinary and sexual functions were self-assessed by patients at baseline and six, twelve, and twenty-four months after diagnosis. The study's results indicated that at eighteen months post-treatment, 8.4% of men were incontinent and 59.9% were impotent. In addition, eighteen months after their surgery, 41.9% of the study's participants reported that their sexual performance was a moderate-to-large problem for them. This study concluded that having a radical prostatectomy

was associated with significant erectile dysfunction and some decline in urinary function among the study's participants (Stanford et al., 2000).

Reis, Netto, Reinato, Thiel, and Zani (2004) conducted a similar study to compare urinary incontinence and erectile dysfunction symptoms reflecting quality of life and the willingness to undergo treatment again in 158 patients treated by radical prostatectomy and brachytherapy between July 1992 and November 2001. Results from a self-reporting questionnaire which consisted of five questions to assess sexual function, four questions to assess urinary incontinence and two questions related to the satisfaction with the treatment and willingness to undergo the same treatment again indicated that 88.2% of patients would elect for surgery again, and 95.5% would undergo brachytherapy again despite the fact that morbidity associated with radical prostatectomy was statistically higher than that associated with brachytherapy and affected self-reported quality of life (Reis, Netto, Reinato, Thiel, & Zani, 2004).

Another study conducted by Lin (2012) evaluated the symptoms and self-assessment of quality of life in men with localized prostate cancer after having had a radical prostatectomy or brachytherapy treatment. Results from this study found that the number of months post-treatment was positively correlated with urinary function and age was negatively correlated with sexual function, bowel function and bowel bother. More specifically, the number of months post-treatment was shown to be related to urinary function; treatment method was shown to be related to bowel function and marital status, age, treatment method and number of months post-treatment were shown to be related to sexual function. Lin's et al. (2012) findings also supported the conclusion that patients who received brachytherapy had better post-treatment urinary functions as compared with prostatectomy patients (Lin et al., 2012).

Radiotherapy, or radiation therapy, is another common treatment modality that aims to sculpt the optimal isodose on the tumour volume while sparing normal tissues (Thariat, Hannoun-Levi, Sun Myint, Vuong, & Gerard, 2013). Often viewed as a less evasive treatment option; the efficacy and tolerance of radiotherapy have been demonstrated by randomized trials in many different types of cancer, including prostate cancer, with a high level of scientific evidence (Donnelly et al., 2010; Giovanessi et al., 2012; Joly, Degrendel, & Guizard, 2010;

Zelevsky et al., 2013). The goal of localized prostate cancer radiotherapy is to cure patients and, as such, the decision-making process must integrate quality of life issues in addition to survival considerations. In comparison with radical prostatectomies, patients treated with external beam radiation have reported less long-lasting urinary symptoms, but more bowel side effects, with no difference in global quality of life (Van den Bergh et al., 2012). While many patients believe that radiation therapy will have less of a negative impact on erections and thus may choose this treatment over surgery as a way to preserve sexual function, data suggests that sexual disorders that were initially viewed as less important have been found to increase over time (Van den Bergh et al., 2012). In other words, research has shown similar erectile dysfunction rates among both radiation and surgical groups at the three-year and five-year post-treatment mark (Potosky et al., 2004). Bowel and gastrointestinal dysfunction are also often cited as adverse side effects of radiotherapy which may result in symptoms such as, but not limited to, rectal bleeding, diarrhea and, progressively over time for some patients, sexual dysfunction (Lund, Kaasa, Wibe, Widmark, & Fransson, 2013).

Gray and colleagues (2013) reviewed patient reported outcomes data collected prospectively using validated instruments that assessed bowel and urinary quality of life for patients with localized prostate cancer who received three dimensional conformal radiotherapy (n = 123), intensity-modulated radiotherapy (n = 153) or proton beam therapy (n = 95). Changes from baseline were then compared within groups at the first post-treatment follow-up (two to three months from the start of treatment) and at 12 months and 24 months. Results demonstrated that although the timing of toxicity varied between the three cohort groups, patients reported similar modest quality of life decrements in the bowel domain and minimal quality of life decrements in the urinary domains at 24 months (Gray et al., 2013).

Hormonal therapies, also known as androgen deprivation therapy, can also pose serious physical side effects for prostate cancer patients since they reduce the levels of testosterone in the body. The side effects of hormonal therapies can be particularly distressing for otherwise asymptomatic men. These side effects can include hot flashes, loss of bone density and increased fracture risk due to osteoporosis, anemia, fatigue, decreased sexual desire or loss of libido, erectile dysfunction, reduced cognitive function, risk of diabetes, risk of cardiovascular disease and fatal cardiac events as well as possible emotional distress (Casey, Corcoran, & Goldenberg,

2012; Grossmann & Wittert, 2012; Higano, 2012; Joly et al., 2006; Jones & Channer, 2014;) Such side effects extend far beyond men's physical bodies by negatively affecting their sense of self, their sexual intimacy and their ability to interact with their significant others (Bokhour, Powel, & Clark, 2007). Hormonal therapies are also often associated with lower quality of life outcomes than other treatment modalities. A recent observational study of 587 patients (equaling 1,518 patient visits) conducted by Prezioso and colleagues (2007) concluded that androgen deprivation therapies were closely associated with a decline in patients' quality of life, particularly in the domains of physical function, energy, and general health status (Prezioso et al., 2007).

Not surprisingly, physical function domains are often cited as core determinants of quality of life within many studies, regardless of selected treatment modality. For example, in 2013, Ferrer and colleagues specifically examined the impact various treatment modalities had on prostate cancer patients' urinary and sexual function. In their recent prospective observational cohort study consisting of a pre-treatment quality of life evaluation and a five-year post-treatment follow-up evaluation to assess the long-term quality of life impact of radical retropubic prostatectomy, external beam radiotherapy or brachytherapy treatments in localized prostate cancer patients, a total of 704 participants with low or intermediate risk disease were recruited between 2003 and 2005. Within this study, quality of life was measured by the Expanded Prostate Cancer Index Composite questionnaire with urinary irritative-obstructive, incontinence, bowel, sexual, and hormonal scores ranging from zero to 100 and the Short Form-36 questionnaire which were administered before patients' initial treatment and during their follow-ups at one, three, six, and twelve months after treatment during the first year, and annually thereafter. Results from this study demonstrated that brachytherapy was the treatment causing the least impact on participants' quality of life as determined by their physical functioning except for moderate urinary irritative-obstructive symptoms (Ferrer et al., 2013).

Watchful waiting, also known as active surveillance or expectant management, is an alternative to treatment for men with low-risk prostate cancer. However, it is unclear within current health literature how health-related quality of life may change over time for men who chose this treatment option. Using the University of California - Los Angeles Prostate Cancer Index and RAND 36-Item Health Survey, Arredondo and colleagues (2008) reviewed health-

related quality of life scores of 310 men diagnosed with prostate cancer, who chose watchful waiting as a treatment choice, between 1990 and 2001. Findings from this study indicated that participants with prostate cancer who chose watchful waiting had better or similar health-related quality of life outcomes compared to men without prostate cancer at the start of the study; with many scores within the physical domain (e.g., sexual function) having decreased more than expected from the aging process alone (Arredondo et al., 2008).

However, a 2012 study conducted by Bergman and Litwin demonstrated that although the overall deleterious impact on health was less traumatic for men who opted for watchful waiting as a treatment option than for those who pursued curative treatment, men on active surveillance also suffered sexual dysfunction and psychological distress. More precisely, five-year outcomes results from their study on the quality of life in men undergoing active surveillance for localized prostate cancer revealed more erectile dysfunction (e.g., 80% versus 45%) and urinary leakage (e.g., 49% versus 21%), but less urinary obstruction (e.g., 28% versus 44%) in men undergoing prostatectomies versus those who opted for watchful waiting. Bowel function, anxiety, depression, well-being, and overall health-related quality of life were similar among both treatment groups after five years, however, at the six to eight-year point, other domains of health-related quality of life, such as anxiety and depression, deteriorated significantly for those who chose watchful waiting (Bergman & Litwin, 2012).

Regardless of the treatment modality selected, many men diagnosed and treated for prostate cancer are at risk for post-treatment psychosocial issues. One of the major psychosocial concerns reported within current health care literature is the fear of cancer recurrence. For example, in 2008, Bellizzi, Latini, Cowan, DuChane and Carroll examined the impact of fear of recurrence on the health-related quality of life of 730 men treated for localized prostate cancer. Results from their study found statistically significant findings ($p < .01$) and demonstrated that improved fear of recurrence, a higher number of post-treatment symptoms, and improved bowel function significantly predicted better mental health scores among participants. Within the physical function domain, improved urinary bother and a lower number of post-treatment symptoms were associated with better physical health (Bellizzi, Latini, Cowan, DuChane, & Carroll, 2008).

A similar, albeit larger scaled study conducted by Hart and colleagues (2008), investigated the impact of treatment satisfaction and fear of recurrence on patients' quality of life after undergoing radical prostatectomy for prostate cancer. This research drew data on 333 patients from the CaPSURE database, a US-based 12,000-man national observational prostate cancer registry. After controlling for age, education, number of comorbid medical conditions, and cancer severity, results from this study demonstrated that lower fear of cancer recurrence ($B = -0.12, p < 0.0001$), higher treatment satisfaction ($B = 0.09, p < 0.001$), and the interaction of treatment satisfaction and fear of cancer recurrence ($B = 0.87, p < 0.05$) significantly predicted higher mental health quality of life score among participants (Hart, Latini, Cowan, Carroll, & CaPSURE Investigators, 2008). This study concluded that understanding prostate cancer patients' fears about cancer recurrence and how these fears could influence physical and mental health were essential components in providing quality care to this growing patient population.

The above studies demonstrate the particular challenges caused by both the cancer diagnosis and its treatments. However, quality of life may be further threatened by the impact of a second treatment on men's overall sense of well-being. Arredondo and colleagues (2007) assessed the impact of a second treatment on men with prostate cancer by comparing differences in health-related quality of life before and after second treatment for men who had asymptomatic prostate specific antigen recurrence with those who did not have biochemical failure. Using the Medical Outcomes Survey Short Form-36 and UCLA Prostate Cancer Index, 175 of the 897 men in this analysis underwent a second treatment (non-adjuvant) for their disease. Results from this study demonstrated that men who received a second treatment presented with more severe disease before radical prostatectomy and had worse general health-related quality of life. In addition, physical function scores related to sexual function and role-physical domains scores showed clinically and statistically significant patterns of decreasing with time. The authors concluded that while health-related quality of life was affected following second treatment for the disease, the actual decline began approximately one year before the commencement of the secondary treatment (Arredondo et al., 2007).

While there is a proliferation of quantitative studies on the physical impact of treatment for prostate cancer on men's quality of life, such as those listed above, many researchers now recognize the need and importance of assessing the impact of this disease and its treatment

modalities on patients' subjective well-being, rather than simply focusing on their survival or health status (Fallowfield, 2002; Stone, Murphy, Matar, & Almerie, 2008). This conceptual shift within quality of life research started in the early 1980s, when social and health researchers moved towards a more inclusive definition of quality of life with the purpose of detecting the non-medical impact of chronic disease, and as a criterion for the evaluation of the effectiveness of medical and psychosocial treatment (Bowling, 2007; Fitzpatrick et al., 1992). The value of a more expanded definition of quality of life was later supported within health research in 1995, when a working group of the World Health Organization (WHOQOL Group, 1995) developed a theoretical definition of quality of life that acknowledged its subjective nature by viewing it as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (The WHOQOL Group, 1995, p. 1403). Ascertaining the patient's perspective and their unique illness experience has led some researchers to move beyond the large-scale quantitative studies, such as those listed above, in favour of smaller, more detailed qualitative accounts of the impact of prostate cancer on the lives of those it affects.

For example, a descriptive exploratory qualitative study conducted by Bahrami (2011) sought to understand the in-depth meanings and aspects of quality of life for cancer patients from different inpatient and outpatient oncology services in a palliative setting in Adelaide, South Australia. Qualitative results identified various contributors to patients' quality of life including physical factors, psychological factors, spiritual connectedness, environmental stimuli and social interactions (Bahrami, 2011). More importantly, the nature of this study's design allowed room for participants to provide an in-depth description of their accounts which then allowed the researcher to more fully comprehend participants' unique experiences (Bahrami, 2011).

1.3.3 The Psychological Impact of Prostate Cancer

A diagnosis of prostate cancer carries with it a significant cognitive and emotional burden, which is amplified as the man and his partner face the potential for changes in their quality of life (Helgason, Dickman, Adolfsson, & Steineck, 2001; Love et al., 2008). In addition, improvements in contemporary detection methods have led to a larger proportion of Canadian males being diagnosed with this disease. As demonstrated by the literature reviewed above, prostate cancer and its treatment options can negatively impact men's quality of life in

multiple spheres. Physiological problems related to treatment choices (e.g., sexual dysfunction, urinary incontinence, bowel changes, body image changes, forced lifestyle changes) can also lead to psychological distress. According to Hsiao and colleagues (2007), psychological and social issues arise in 30-50% of prostate cancer patients regardless of the stage and progression of cancer or the type of treatment they select (Hsiao, Loescher, & Moore, 2007). The most commonly cited forms of psychological distress in men with localized prostate cancer relates to changes in their self-perception, guilt and remorse after a diagnosis, distress in decision-making, fear with regards to recurrence of the cancer after treatment, an impending fear and recognition of their own mortality as well as an overall sense of anxiety related to the uncertainty created by this disease (De Sousa, Sonavane, & Mehta, 2012). In fact, anxiety tends to be the most often experienced symptom for men with prostate cancer (Roth, Weinberger, & Nelson, 2008). Many men may also report irritability or depression, with a past history of depression shown as the biggest predictor of illness-related depressive symptomology (Sharpley, Bitsika, & Christie, 2014).

A recent study conducted by Kohler and colleagues (2014), sought to determine the level of psychological distress (e.g., anxiety, depression) and adjustment to disease in patients who underwent radical prostatectomies. Using the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) to evaluate 329 prostate cancer patients before surgery as well as three, six, and 12 months after surgery; they found that both urinary symptoms and baseline psychological distress were relevant predictors for psychological distress after surgery and that adjustment to disease was highest before surgery and had significantly reduced at three and six months post-surgery (Kohler et al., 2014). While the authors concluded that participants in their study were generally resilient to the experience of localized prostate cancer (e.g., meaning able to adjust well psychologically after surgery), they conceded that between 8% and 20% of patients would benefit from formal mental health initiatives (Kohler et al., 2014).

In a systematic review of the psychological aspects of the prostate cancer experience, Bloch and colleagues (2007) also concluded that early signs of distress, particularly depression and anxiety, were indicative of a poorer psychological prognosis. In addition, they found that coping (e.g., involving interpersonal awareness and expression of emotions) was linked to better

adjustment while a sense of helplessness was understood as a direct correlate to low self-esteem and depression (Bloch et al., 2007).

The psychological adjustment required of men facing a diagnosis of prostate cancer is especially complex, given the potential trajectory of the disease, from the time of diagnosis with its immediate impact to the decision-making process and post-treatment life. In fact, when men are diagnosed and treated for prostate cancer, many experience what Chamaz (1995) has termed “identity dilemmas” (Charmaz, 1995). This is due to the fact that the treatment and side effects endured when combating this disease can pose serious threats to their traditional scripts of masculinity (e.g., being unemotional, being self-reliant, being powerful, being independent, defining one’s worth in terms of sexual potency) (Zaider et al., 2012) thus forcing them to redefine their sense of self. In fact, in order to fit within the socially and culturally appropriate definitions of what it means to be a “man,” many men may risk their health by undertaking behaviours to preserve their sense of masculinity such as avoiding seeking medical care or minimizing their symptoms account when speaking to their health care professionals (Nicholas, 2000; O'Brien, Hunt, & Hart, 2005; Oliffe & Thorne, 2007). In addition, men’s commitment to these gender scripts may continue to have a negative impact on their overall health by intensifying their adjustment to treatment for prostate cancer “by depriving them of sources of emotional and social support while enhancing the salience of losses in sexual function” (Burns & Mahalik, 2007, p. 253). In fact, it has been shown that the extent to which men view their cancer as inconsistent with their masculinity exacerbates declines in prostate-related functioning following cancer treatment (Hoyt, Stanton, Irwin, & Thomas, 2013). However, while men’s psychological adjustment to a diagnosis of prostate cancer must be recognized within a socially embedded and culturally defined experience, it is also important to recognize the extended social impact of this disease.

1.3.4 The Social Impact of Prostate Cancer

It has been well documented that prostate cancer and its treatment not only impacts the cancer patient but both members of the couple, especially in the areas of intimacy, sexual functioning and communication (Badr & Krebs, 2012; Droupy, Al Said, Lechevallier, Colson, & Giuliano, 2013; Galbraith, Fink, & Wilkins, 2011; Lafaye et al., 2014). As with many chronic illnesses, treatment of prostate cancer and its after effects place an immense burden on the

physical and emotional resources of the couple because of treatment-related consequences. Survivors and their significant others have expressed fear, anger, sadness, disappointment and loss as a result of their experiences with treatment for this disease (Galbraith et al., 2011; Oba et al., 2014; Fagundes, Berg, & Wiebe, 2012). In addition, research has shown that the manner in which each partner experiences the diagnosis and consequences of treatment influences the other partner's evaluation of the illness experience. For example, Kim (2008) examined the dyadic effects of psychological distress on the quality of life of couples dealing with cancer and found that although each person's psychological distress was the strongest predictor of their own quality of life, a patient's partner's distress, and (dis)similarity in distress of the couple also played significant roles in one's quality of life (Kim et al., 2008).

Another recent study conducted by O'Shaughnessy and colleagues (2013) explored issues related to sexual function and relationships, for men and their wives or partners, following diagnosis and treatment for prostate cancer. Key findings pointed to differences between men and their wives'/partners' assessment of how this disease had impacted the men's sense of masculinity. More specifically, results revealed that 71% of wives/partners believed that prostate cancer had impacted on their partner's feelings of masculinity compared to only 42% of men who felt that this was the case.

Galbraith, Fink and Wilkins (2011), also found that couples who are survivors of prostate cancer are faced with interruptions in their intimate relationships, communication, and overall quality of life. In addition, their research highlighted the lack of educational and psychological resources available to both patients and their significant others when faced with a diagnosis of prostate cancer (Galbraith, Fink, & Wilkins, 2011). However, current research suggests that increased social support and better communication can help couples develop strategies to cope with these changes and disruptions (Galbraith et al., 2011). While some couples may exude avoidance strategies to defend against worry about cancer and anticipated post-treatment quality of life changes, current literature suggests that these barriers may be modifiable if couples can learn to accept sexual losses and adopt sexual rehabilitation strategies (Wittmann et al., 2013). In other words, coping strategies adopted by patients with prostate cancer and their spouses can have a positive effect on their emotional state and overall quality of life. In fact, results from a recent study by Lafaye (2014) demonstrated that coping strategies

used by patients or spouses play a key role not only in their own well-being but also in their partner's sense of well-being. In addition, results confirmed that when prostate cancer patients used problem-focused coping strategies or displayed social support-seeking behaviours, both they and their partners experienced fewer anxiety and depressive symptoms (Lafaye et al., 2014).

1.4 Health Care Service Delivery in the North

The realities of a diagnosis of prostate cancer, as it has been clearly demonstrated within the academic literature, impact men's physical, psychological and social well-being (Badr & Krebs, 2012; Davison, So, & Goldenberg, 2007; Droupy, Al Said, Lechevallier, Colson, & Giuliano, 2013; Galbraith, Fink, & Wilkins, 2011; Lafaye et al., 2014; Love et al., 2008; O'Rourke, 2007; Prezioso, Galasso, Di Martino, & Iapicca, 2007). Difficult decisions are required to be made; often within a context of risk and uncertainty (Adam, Beck, & van Loon, 2000; Hamilton et al., 2013; Kazer et al., 2013; Jayadevappa et al., 2009). For many men, a diagnosis of prostate cancer forces them to rely on an unfamiliar health care system. As such, understanding the capacity of prostate cancer patients to access the resources needed to maintain and sustain their ongoing well-being, while also taking into account the contextualized intricacies surrounding access and distribution of these shared resources within a culturally and socially negotiated manner, is central to the development of a deeper understanding of the effects of this disease on men's cancer treatment decision-making processes and their overall quality of life (Ungar, 2012; Ungar et al., 2007).

In order to appreciate what a diagnosis of, and treatment for, prostate cancer implies for Francophone men living in Northeastern Ontario, a review of the broader parameters of Ontario's health service delivery model is required. As such, the realities of northern and rural service provision will be discussed and specific attention will be given to the disparities that exist within this system for patients belonging to this linguistic minority group.

1.4.1 The Geographical & Cultural Contexts of Northern Health Care Services

The Ontario health care system underwent a major structural reform in the mid-2000s with the introduction of regional health authorities called Local Health Integration Networks

(LHINs). Under the *Local Health Systems Integration Act*² of 2006, 14 local health integration networks were established; each responsible for a designated geographical area. On April 1, 2007, the local health integration networks assumed responsibility for the delivery of major health services including hospitals, community support service organizations, community care access centres, community mental health and addiction agencies, community health centres, and long-term care facilities (Barker, 2007). This shift towards a regional strategy for health care provision established that it was the people and services located within the communities that were best equipped to understand and administer the actual health care needs of the population in a manner that was both equitable and fiscally responsible (Fenn, 2006). The intent of this decentralized approach to health care management and service delivery was to focus on health prevention and community based care rather than on centralized institutional services. Given that Northern Ontario covers approximately 800,000 square kilometres, two separate regional health authorities were established. More specifically, the Northeast Local Health Integration Network (NE LHIN) and the Northwest Local Health Integration Network (NW LHIN) were instituted to facilitate health service delivery to the North's ten territorial districts, 144 municipalities, 106 First Nations and over 150 unincorporated communities.

Northern Ontario has five mid-sized urban cities, namely: North Bay; Greater Sudbury; Sault Ste Marie; Timmins and Thunder Bay. It also includes a variety of smaller, more rural communities distributed across its large land area. With a population of approximately 808,448 people (2008 annual population estimates) representing only 6% of the provincial population, Northern Ontario has a population density of approximately one person per square kilometre, compared to 111 persons per square kilometre in Southern Ontario (Ministry of Northern Development and Mines, 2009). Generally speaking, Northern Ontario residents lag behind the rest of province with regards to several socio-demographic factors. Specifically, as demonstrated in Table 4 (below), populations living in Northern Ontario tend to be older, have lower educational attainment, higher unemployment rates and tend to be more reliant on government transfer payments than the rest of the province.

² *Local Health Systems Integration Act 2006*, S.O. 2006

Table 4

Demographic and Socioeconomic Characteristics of Northeastern Ontario, Northwestern Ontario, and Ontario, 2004

	Northeastern Ontario	Northwestern Ontario	Ontario
Population aged 65 or above	14.8	13.3	12.9
Unemployment rate (%)	9.8	9.6	6.1
Percentage of population without completed high-school education	33.4	32.6	25.7
Percentage of income from government transfer payments	15.6	13.2	9.8
Percentage of economic families below low income cut-off	12.5	8.9	11.7

Sources: Sources: Socio-Economic Indicators Atlas: Northeast LHIN (Toronto: Health System Intelligence Project, Ministry of Health and Long-Term Care, 2006). Socio-Economic Indicators Atlas: Northwest LHIN (Toronto: Health System Intelligence Project, Ministry of Health and Long-Term Care, 2006).

In addition to these population health trends, there are several additional challenges associated with providing quality health care services to Northern Ontario communities that are dispersed across a large geographic area such as geographic remoteness, long distances to health centres, low population density, lower availability of health care professionals and inclement weather which can affect both air travel and road conditions (Ministry of Health & Long-Term Care, 2011). While poor population health is rarely the result of a single factor, mainstream consensus in Northern Ontario typically attributes various health woes on difficulties in gaining access to health care (Tesson, 2009). However, access to health care must be considered in reference to the broader context that recognizes multiple dimensions of health care quality such as, genetic predisposition, social circumstances, environmental exposure, lifestyle behaviours in addition to issues related to access to health care (Reichstadt, Depp, Palinkas, Folsom, & Jeste, 2007; Yashin et al., 2010;).

1.4.1 Northeastern Ontario

Since the intent of this study is to focus attention on the illness experiences of Francophone prostate cancer patients from Northeastern Ontario, a closer look at the geographic parameters of this region is warranted. As previously mentioned, health service provision within Northeastern Ontario is governed by the Northeast Local Health Integration Network (NE LHIN). The NE LHIN, one of the largest of the 14 LHINs in Ontario, is responsible for the planning, funding, integration and evaluation of health care services for more than 565,000 people across 400,000 kilometres (Local Health Integration Network, 2014). Although Northeastern Ontario contains several larger urban cities (Greater Sudbury, Timmins, Sault Ste Marie and North Bay), it is primarily made up of much smaller, more rural communities that were established with the development of the mining and forestry industries within the region.

Approximately 23% of Ontario's Francophone population (127,265 in 2011) resides in Northern Ontario, mostly in Northeastern Ontario. In fact, almost one in four residents living in Northeastern Ontario are Francophone (Statistics Canada, 2011a). In addition to the socio-demographic indicators presented above that highlighted the differences between Ontario's northern and more rural population, research has shown that Francophones living in the North also tend to be older, less educated, have a higher rates of tobacco use, and be less active in the labour market than the rest of Ontarians (Allaire & Picard, 2005). In fact, when asked, Francophones living in Northeastern Ontario were shown to be the least likely to rate their health as "very good" or "excellent" (Allaire & Picard, 2005). Even with a significant number of Francophones seeking health care in Northern Ontario, there are relatively few health services offered in French (Bouchard et al., December 2012; Bouchard, Makvandi, Sedigh, & Van Kemenade, 2014;). When French language services do exist, they are subject to great temporality since there currently does not exist any formal system to coordinate existing assets in order to provide dependable and reliable care (Drolet et al., 2014).

For Francophone men living in Northern Ontario, a diagnosis of prostate cancer forces them to navigate a distributed health care system since the specialized procedures and services they often require are unavailable within their home communities. As such, their perceptions of their illness experiences are necessarily influenced by their access to diagnostic and treatment services, their social environments and their social support networks.

Language is an important factor when attempting to understand how Francophone patients construct their realities in the face of prostate cancer since it necessarily affects various dimensions of the disease management process; including patient-practitioner interactions. As contended by Lev Vygotsky (1962), language must be understood as socially developed and thus influences one's thoughts and behaviour. Research on the influence language within the physician-patient interaction has shown that patients with poor language proficiency received poorer quality care, less information during prognostic discussions and showed poorer recall of information (Bowen, 2008; Butow et al., 2013; Butow et al., 2011; Diamond, Luft, Chung, & Jacobs, 2012).

For example, a hermeneutic research study conducted by Marshall (2011) emphasized the impact of language on the ways in which health care professionals related to patients and provided their clinical services, as well as the way in which patients themselves conceptualized their role in the health care encounter (Marshall, Medves, Docherty, & Paterson, 2011). Findings from this study emphasized the need to be more inclusive by avoiding the use of exclusionary jargon (e.g. discipline-specific medical terminology) so that all members of the health care team, including patients and families, could work collaboratively and increase positive health outcomes (Marshall et al., 2011).

The importance of language during medical encounters becomes even more relevant when one considers the additional complexities surrounding medical encounters where the physician and the patient do not speak, or understand, the same language. For example, Butow and colleagues (2011) conducted a study on the potential communication challenges among oncology consultations of linguistic minority immigrants (Arabic, Chinese or Greek) with and without interpreters versus linguistic majority Anglo-Australian patients. Results showed that physicians spoke less to immigrants with interpreters than to Anglo-Australians (1443 versus 2246 words, $p = .0001$), spent proportionally less time on cancer-related issues ($p = .005$) and summarizing/informing ($p = .003$); and more time on other medical issues ($p = .0008$) and directly advising ($p = .0008$). In addition, results showed that physicians tended to delay responses to or ignore more immigrant cues than Anglo-Australian cues (13% vs. 5%, $p = .06$).

Another recent study by Bouchard and colleagues (2012) evaluated this particular dynamic among elderly Francophone patients and Anglophone physicians. Results from this study highlighted the complex nature of language issues within medical interactions and recognized that patients' ability to effectively communicate and trust their health care provider were central challenges among elderly Francophone patients. More specifically, their research demonstrated that communication complications within the physician-patient dynamic were most often due to assorted psychological or social factors such as the specialization of medical language and fear of not being able to comprehend it thoroughly, the rushed nature of most medical encounters, and the challenge of understanding and expressing oneself in English, including expressions of emotion or pain (Bouchard et al., 2012). Thus, it is clear that linguistic minority groups, such as Francophone prostate cancer patients, may face additional challenges when accessing services within the current health care delivery model and as such, warrant a more detailed exploration of the particularities of their illness experiences.

1.5 Chapter Summary

Prostate cancer touches numerous facets of men's lives; it can affect their physical and psychological health, their intimate and social relationships, their sexuality, their outlook and understanding of aging and what it means to them to be placed in a position of vulnerability in the face of this disease. Chapter 1 provided a detailed overview of the current literature related to men and their health with specific attention placed on the various social theories of aging that co-exist within a broader conceptualization of men's experiences with prostate cancer. In addition, this chapter offered the reader a thorough narrative on key topics related to the development of prostate cancer. A review of current prostate cancer statistics was given and a comprehensive account of the various risk factors, screening and detection methods, and available treatment options was provided. Information related to the risk factors associated with various treatment modalities was presented, with a specific focus given to the potential treatment side effects on men's physical, psychological and social quality of life. In addition, the impact of medical uncertainty and patients' self-assessment of treatment risk on their quality of life and on their capacity for resilience was explored. This chapter concluded by exposing some of the unique geographical, cultural and linguistic contexts specific to the health service delivery model

influencing the Northeastern Ontario Francophone participants of this study. In the following chapter, the theoretical framework and conceptual model governing this study will be discussed.

CHAPTER 2: THEORETICAL FRAMEWORK & CONCEPTUAL MODEL

In the present chapter, we evolve beyond the quantitative dimensions of the disease in order to better understand the theoretical and conceptual parameters that governed this study. We will begin with an overview of social constructivism prior to delving deeper into the conceptual model selected to support the framework of this study. Specific attention will be placed on conceptualizing Francophone participants' quality of life and resilience within a framework that recognizes that their illness experiences are both created and influenced by a their geographic location, cultural background and social interactions with others.

2.1 Theoretical Approach: Social Constructivism

Men diagnosed with prostate cancer face a multitude of physical, psychological, and social issues. However, existing research has typically focused on specific time frames such as those newly diagnosed with an initial occurrence or at the time of a second recurrence, or men with advanced disease. Hence, few studies have examined men's subjectively constructed experiences across the illness trajectory and the impact of prostate cancer on their everyday lives. More importantly, research on Francophone prostate cancer patients from Northeastern Ontario and how these particular men negotiate and make sense of their illness-related issues given the particular social, geographical and cultural contexts of their socially constructed illness experiences is non-existent.

Social constructivism was the theoretical framework used within this study. It is rooted in both philosophy and sociology (Pass, 2004) as well as closely associated with the developmental theories of Lev Vygotsky (1962). Within the social sciences, the terms social constructivism and social constructionism are often used interchangeably (Burr & Ebrary, 2003; Hibberd & SpringerLink, 2005) and are frequently described as a developmental theory emerging in response against the conflict theory (Burr & Ebrary, 2003; Burr & Ebrary, 1995). Conflict theory, which argued that society is best understood as a complex system competing for limited resources (e.g. money, power, influence, etc.), highlighted the inherent inequalities within society whereby some people and organizations had more resources and used those resources to maintain their positions of power in society (Collins & American Sociological Association,

1983; Coser, 1972). In time, social constructivism emerged in an attempt to redirect focus away from the conflict theory and back onto the individual members within society. Social constructivism thus aimed to better ascertain each person's impact on his or her own experiences, and personalized constructions of their realities based on said experiences.

Within North America, social constructionism was introduced into the social sciences by Peter Berger and Thomas Luckmann in their 1966 book entitled *Social Construction of Reality* (Berger & Luckmann, 1966). Berger and Luckmann, considered by most as the pioneers of this framework, acknowledged the influence of Mead, Marx, Schutz and Durkheim on their writings and positioned social constructivism inclusive of both subjective and objective realities. In other words, they held the belief that reality cannot exist outside what is produced and reproduced during social interactions. In their writings, Berger and Luckmann (2006) were concerned with the nature and construction of knowledge; how it emerged and how it came to have significance for society. More so, they believed in the existence of "expert knowledge," created out of the division of labour, the emergence of more complex forms of knowledge and the economic surplus. More specifically, they asserted that this expert knowledge was developed by people devoting themselves full-time to their subject matter and thus allowing them to have a more in-depth knowledge base on the subject thereby leading to increased status and power positioning in reference to their expert domain.

This knowledge-power dynamic is all too familiar within the clinical-medical setting; as evident within the plethora of academic literature on the topic (Jordanova, 1995; Lin, Tzeng, Chiang, & Chiang, 2012; McWilliam et al., 2009; Schaubert, Hecht, Nouns, & Dettmer, 2013; Steinbrook & Redberg, 2013). For example, Hunter (1991) recognized the interplay of the knowledge-power or knowledge-status dynamic within the field of medicine, whereby the biomedical model of defining illness dedicated much more time to the study and control of health situations (e.g. diagnosing illnesses) and as a result, medical practitioners were seen as experts within the field who thus enjoyed a privileged position in society (Hunter, 1991). Brown (1995) also examined the social construction of the illness experience within medical sociology, emphasizing the need for a more phased approach to knowledge development within medicine, the need for an initial concern with the social discovery (or diagnosis) of the medical issue and a

secondary emphasis on the illness experience, including the various stages of treatment and outcome (Brown, 1995).

As previously mentioned, Berger and Luckmann (2006) understood society existing simultaneously as both an objective and subjective reality. They recognized that individuals form their experiences of reality through their interactions with others who share common goals, interests, or assumptions (Berger & Luckmann, 2006). In denying the existence of an objective reality, constructivists like Berger and Luckmann (2006) recognized the existence of multiple, dynamic realities that are all socially and experientially based. More specifically, they believed that within the subjective nature of knowledge creation, conversation was the most important means of maintaining, modifying and reconstructing a person's subjective reality thus highlighting the conceptual importance of language within the social construction of reality.

In applying the framework of social constructivism to the present study, it was presumed that the participants created their own subjective meanings of their cancer illness experience. It was further assumed that these meanings were influenced by their interactions with others, as well as their own personal values and their cultural backgrounds. As in the works of Berger and Luckmann, language was also recognized within this study as a key component in the creation of participants' illness experience. As such, a thorough investigation of these subjective meanings was undertaken in order to gain a greater understanding of the manner and mechanisms participants utilized in the construction and reconstruction of their lives (and quality of life) when faced with this particular disease experience.

According to Corbin and Strauss (1987), along a person's biographical life journey, various aspects of the self-differ in relation to the contextual situations experienced by an individual (Corbin & Strauss, 1987). Such individualized situational events and occurrences enable most people to adapt, change and transform their identity in light of a specific illness situation and find options or meanings from this particular illness experience. Within this context, the process of social construction is even more germane as it provides a set of significant explanations and interpretations that are not accounted for in the modern biomedical model of illness that primarily focuses on illness identification and disease management protocols (Martin & Peterson, 2009).

Epistemologically, constructivists emphasize the transactional and subjective interrelationship between the researcher and the participant in the co-construction of meaning (Charmaz, 2006; Kruger, 2002; Philpott & Batty, 2009; Thofehrn & Leopardi, 2006). Constructivists attempt to connect as closely as possible to the inside of the research experience, however recognizing that they cannot replicate the actual experience of the participants (Charmaz, 2006:131). Instead, researchers are understood as active participants in the research endeavour, rather than objective observers, and their actions, beliefs and assumptions are to be acknowledged as an inevitable part of the analysis and interpretation of the research findings (Guba & Lincoln, 2005; Lee, 2012; Mills, Bonner, & Francis, 2006).

The aim of social constructivism is the understanding and reconstruction of the conceptualizations that people initially hold, leading towards a greater comprehension of the inquiry while still being open to new interpretations as new information arises (Guba & Lincoln, 2004). Within this paradigm, knowledge is understood, created and modified in direct reflection of one's current understanding in combination with updated or new information (Guba & Lincoln, 2004). As such, social constructivists refute the existence of objective fact by denying that knowledge is a direct perception of reality and instead ascertain that all knowledge is derived from looking at the world from one perspective, or another, within the context of a particular culture, and within a specific time frame (Burr & Ebrary, 2003). In addition, social constructivists acknowledge that language is a pre-cognition for thought since people are born into a world where the conceptual frameworks and linguistic concepts they will use throughout their lifetime already exist (Burr & Ebrary, 2003). Within this paradigm, the categories and concepts used to help us understand the experiences we live, such as illness, are historically and culturally moulded. More specifically, within the example of a person's encounter with ill health, the very definition of illness extends beyond the simple presence of pathology since, as stated by Burr (2003), illness is a "deeply social matter involving the interpretation of our experience within our particular cultural context of assumptions, norms, values as well as the economic structure of our society" (Burr & Ebrary, 2003, p. 40). In other words, the manner in which someone experiences illness is relative to the culture, time and place in which this sickness is encountered.

Increasingly, researchers (Gordon & Cerami, 2000; Gray, Fitch, Fergus, Moynihan, 1998; Mykhalovskij, & Church, 2002; Oliffe, 2003; Oliffe & Thorne, 2007) are advocating the use of a social constructivist framework for studying male cancers in order to capture the impact of subjective meanings and contextual factors, rather than simply viewing the “men with cancer as passive recipients of the effects of biological, psychological, or social factors” (Oliffe, 2003, p. 43) of the disease. Gray and associates (2002), for example, understood the value of this approach in their grounded theory study of men’s adjustment to sexual dysfunction following prostate cancer (Gray et al., 2002). Using a constructivist framework of masculinity, their research results showed that social factors such as work and family influenced (and were influenced by) these men’s experiences with illness as they were forced to renegotiate their performances of masculinity (Gray et al., 2002).

A social constructivist framework was also used in a narrative analysis of two Black men’s experiences with prostate cancer and the interconnections with hegemonic masculinity that was completed by Gray, Fitch and Fergus in 2005. Results from this particular study demonstrated how the interaction of race with health and illness was neither predictable nor consistent at the individual level (Gray et al., 2005). These men, like all men with prostate cancer, had diverse experiences which were subjective in nature and influenced by a wide array of personal and societal factors. The importance of using a social constructivist framework in the study of men’s illness experiences is further supported by Creswell (2007), who stated that subjective meanings attributed to the unique experiences in one’s life are “formed through interactions with others and through historical and cultural norms that operate the individuals’ lives” (Creswell, 2007, p. 21). Thus, for men who have experienced treatment for prostate cancer, the process of constructing the experience and assigning meanings to it is highly personal and dependent on the contexts in which they find themselves (Martin & Peterson, 2009). In the following section, a closer look at some of the key concepts that helped frame this study will be explored.

2.2 Conceptual Framework

As it has already been established, the intent of this study was to move beyond the biomedical model of prostate cancer in order to understand how Francophone men, belonging to a linguistic minority group within an often isolated geographic context, described their overall

experiences with prostate cancer and its effect on their overall quality of life. Within a social constructivist framework, the influence of the Francophone culture on participants' experiences with prostate cancer was recognized as being embedded within a linguistic, geographic and cultural context.

2.2.1 Northern Ontario – Looking Beyond the Geography

Within the social constructivist paradigm, there is a deeply rooted understanding that *place* is ineluctable in creating inquiry outcomes (Guba & Lincoln, 1994). While the concept of place in terms of its geographic distribution and location is not new, to rely solely on this limited definition would neglect a larger contextualization needed to understand the importance of its influence on research inquiry. As such, within this study an emphasis on place will also be established from a socially constructed perspective. It will be strongly associated with the cultural meanings embedded within the geographic construct of residence and community structure (urban/ rural/ remote) as well as the social experiences of illness of participating prostate cancer patients and their interactions with their health care providers (Carolan, Andrews, & Hodnett, 2006).

Operationally, within the parameters of this study and in a geographic sense, *place* referred to the larger geographic location of Northeastern Ontario, specifically focusing on communities that possessed a higher concentration of Francophones. Also of importance to this study is the reality that Francophone communities within Northeastern Ontario which are broadly dispersed across a vast geographic catchment area and as such, face particular challenges related to geographic isolation (e.g., distance, climate) and limited access to specialized health care, not to mention the challenges these residents encounter when trying to access to Francophone health care practitioners or medical specialists who can deliver specialized care in the French language.

A variety of lifestyle or health related behavioural factors, material factors (e.g., the environment and living standards) and psychosocial factors (e.g., stress and risk taking) can have a major impact on one's health. Thus, the concept of *North* as it is conceptualized within this study, extends far beyond the geographic location of residence of Northeastern Ontario participants. In fact, being from the north implies a particular understanding of the social and cultural living conditions that necessarily impact men's access and experience within the health

care delivery model. Since many participants within this study lived in smaller, more rural communities, their location of residence within Northeastern Ontario was understood as an important factor in their cancer experience since this geographic isolation, and the implications of this isolation on their health and access to specialized health care services was assumed to directly affect their pre- and post- quality of life.

The study of place within health and policy literature is not new (Du Plessis et al., 2002; Pitblado, 2005; Pitblado et al., 1999; Pong & Russell, 2003). In fact, current literature often cites northern and rural place of residence as a key factor impacting population health (Romanow, 2002). Many rural communities within Northeastern Ontario face a number of challenges related to their aging population demographics, economic difficulties and socio-demographic challenges (Pitblado, 2005; Pong & Pitblado, 2001). Coupled with the additional challenges of higher unemployment rates, lower educational opportunities and less healthy lifestyle choices, residents within these communities have been shown to be in more vulnerable positions than their urban counterparts (DesMeules et al., 2006).

2.2.1 Definitions of Rural and North

It is well recognized that conceptualizing what is meant by “rural” and “north” or “northern” is challenging (Pitblado, 2005; Pitblado et al., 1999; Pong & Russell, 2003; Romanow, 2002). Rurality, within its most basic conceptualization, is defined as anything outside of urban areas (Du Plessis et al., 2002). Northernism (or northern or north), on the other hand, can include both urban and rural (or remote) communities that are broadly distributed across Ontario’s vast geography.

Several conceptualizations of “rural” exist within current academic literature, although no standard definition exists. In fact, many researchers view rurality as a binary measurement against urbanism or on a sliding continuum where the gradient between rural and non-rural areas may be unclear and difficult to define due to their ever-changing status (Pong & Russell, 2003). For example, Statistics Canada utilizes the Metropolitan Influence Zones (MIZ) methodology to define populations living outside of the commuting zones of *census metropolitan areas/census agglomeration* (CMA/CA). Within this approach, *metropolitan influence zones (MIZ)* that lie outside of a commuting zone of census metropolitan area or census agglomeration are classified

based on the percentage of employed labour workforce living in the census subdivision in the CMA/CA urban core. These zones are defined as being either a “Strong MIZ” (e.g. 30% or more), “Moderate MIZ” (e.g. 5% to 30%), “Weak MIZ” (0%-5%) or “No MIZ” (Statistics Canada, 2011c). Within this classification, Statistics Canada defined rural and small town as communities outside the commuting zone of larger urban centres, outside census metropolitan areas and outside other urban areas, with a core population of 10,000 or more residents (Statistics Canada, 2011c).

Although widely used in ministry publications, this definition was viewed as being too restrictive for the context of this present study. Specifically, this delineation was not selected because it did not account for many of Northeastern Ontario’s larger communities (over 10,000 residents) that exist within a largely distributed rural geography and can face many of the same health concerns and health service challenges as smaller, more rural communities.

Another commonly used definition of rurality stems from the Ministry of Health and Long-Term Care’s Underserviced Area Program (Ministry of Health and Long-Term Care, 2013). This physician recruitment and incentive program establishes parameters for funding programs such as continuing medical education, funding opportunities for locums and incentive stipends for new medical graduates setting up practices within northern and rural communities. Within this framework, communities are assigned a weighted rurality grade, named ‘Rural Index of Ontario’ (RIO) score, based on three primary factors: extended travel time to an advanced referral centre, extended travel time to a primary referral centre, and population (count and density) (Ministry of Health and Long-Term Care, 2010). Within this conceptualization, communities with a rural index of 40 or more are considered ‘rural’ and are therefore eligible for additional funding support³.

This paper recognizes that rurality is not an absolute, rather it is understood as a fluid assessment of a particular community’s geographical status within a multifactorial system of influence. Although the Rurality Index of Ontario definition more closely aligns with the

³ A detailed list of Ontario communities by Rurality Index of Ontario score is available at: http://www.health.gov.on.ca/en/pro/programs/northernhealth/rio_score.aspx

parameters of this present work, this paper also views rurality as along a continuum, whereby some Northeastern Ontario communities may face larger or smaller health challenges depending on where they find themselves on this gradient.

The reality of health care delivery within the Northeastern Ontario, a largely dispersed geographic landscape that is home to many smaller, more rural communities, is a question that has never been fully explored. While a particular focus on prostate cancer is central within this study, it is only one example that was chosen to highlight the complexities and realities experienced by within the current health care delivery model.

2.2.2 Linguistic Minority Francophones

According to the 2011 census, Ontario continues to be home to the largest population of Francophones in Canada outside of the province of Québec, numbering at 611,500 and representing 4.8% of Ontario's population (a 4.9% increase since 2006) (Statistics Canada, 2012). In addition, most of the province's Francophone population reside in Northeastern Ontario. But the question remains as to who is considered to be part of this identified linguistic minority group.

For statistical purposes, Statistics Canada has previously defined Francophones as only those whose mother tongue was French, which in 2011, represented approximately 7.3 million Canadians (Statistics Canada, 2012). However, the Francophone community lobbied against the restrictive nature of this definition leading the government to adopt a more inclusive definition of what it means to be a Francophone. This revised definition, adopted in 2009, now also captures those whose mother tongue is neither French nor English, but who have a particular knowledge of French as an Official Language and use the French language at home (Government of Ontario: Office of Francophone Affairs, 2011). Recognizing the importance of a more inclusive understanding of the definition of what it means to be a Francophone within Northeastern Ontario, participants within this study were considered to be Francophone if they most commonly spoke French in their daily lives and identified themselves with the Francophone culture or as part of the Francophone community, rather than men whose origins are French, but never knew or no longer speak the language. This broader definition, adapted from the work of Robert Stebbins (2000), does not require that French be the person's mother tongue, as long as it

is routinely used in a central sphere of everyday life, such as at work, leisure or inside the home and that there is a self-identification with the Francophone culture (Stebbins, 2000).

Results from a recently released report by Bouchard and colleagues (2014), which analyzed data from the Canadian Community Health Survey (2001-2009), confirmed health inequalities experienced by Francophones aged 65 and older in Ontario. More specifically, their analysis showed that Francophone seniors in Ontario belonged more often than the rest of Ontarians to a low-income category, had a lower level of education, and were more likely to reside in rural or remote areas (Bouchard, Makvandi, Sedigh, & Van Kemenade, 2014). In addition, when considering established health indicators, results from this study also demonstrated that a greater proportion of Francophone seniors were overweight or obese, less physically active, were more likely to report poor physical and mental health, and more often suffered from at least one chronic disease compared to the total population of Ontario (Bouchard et al., 2014). Senior Francophones living in Northern Ontario reported even greater disparities in terms of the lack of education (e.g., less than secondary education) and their income in comparison to their central/south-west, east/south-east and overall provincial counterparts (see Table 5).

Table 5

Senior Francophone Population Aged 65+, by Region

	Ontario Total	Central/ South-West	East/South- East	North
Less than secondary education	23.3%	50.6%	49.8%	67.4%
Income LOW	19.8%	24.9%	37.2%	47.2%
Income HIGH	20.1%	11.1%	8.1%	3.2%

SOURCE: Bouchard, Makvandi, Sedigh and Van Kemenade (2014)

Apart from those living in the province of Québec, Canadian Francophones represent a linguistic minority group and as such, often find themselves occupying socially inferior positions which contribute to certain disadvantages on the health plan side of things (Bouchard & Desmeules, 2011). Within this context, Francophones living in Northeastern Ontario may not only face access barriers caused by the mass shortages of physicians and specialized care within their communities; they may also be required to mitigate issues related to the inability to access health services in their own language. Scientific literature has clearly demonstrated the impact of language barriers on health care provision (Bouchard et al., 2012; Butow et al., 2012; Diamond, Luft, Chung, & Jacobs, 2012; Komaric, Bedford, & van Driel, 2012; Ngwakongnwi, Hemmelgarn, Musto, Quan, & King-Shier, 2012). In fact, current research has proven that language barriers strongly influence whether a patient elects to seek medical attention in the first place, is able to voice their concerns, feels understood by the physician, and is able to properly follow instructions regarding medications and follow-up procedures (Bowen, 2001; Butow et al., 2010; Jacobs, Shepard, Suaya, & Stone, 2004; Harmsen, Bernsen, Bruijnzeels, & Meeuwesen, 2008; Kilbridge et al., 2009; Lourens, 2013; De Maesschalck, Deveugele, & Willems, 2011). Moreover, utilization of health care services among patients with limited English proficiency has been shown to be limited in terms of their access to preventative services (Jacobs, Shepard, Suaya, & Stone, 2004; Woloshin et al., 1997), thus causing an increased financial burden on the health care system since they are more likely to be referred to a specialist (Bowen, 2001) or to have the first interaction with the health care system in an acute setting (Kannan & Veazie, 2014; Van den Bergh et al., 2013).

Thus, belonging to an official language minority group may influence patients' quality of care (Bouchard et al., 2014; Bouchard et al., 2012; Bowen, 2001; Diamond et al., 2012; Drolet et al., 2014). In fact, Bouchard et al. (2012) highlighted the complex nature of language issues within medical interactions and recognized that the ability to effectively communicate and trust their health care provider were central challenges for elderly Francophone patients. More specifically, these communication complications were most often due to assorted psychological or social factors such as the specialization of medical language and fear of not being able to comprehend it thoroughly, the rushed nature of most medical encounters, and the challenge of understanding and expressing oneself in English, including expressions of emotion or pain

(Bouchard et al., 2012). Hence, it is clear that Francophone prostate cancer patients may face additional challenges when accessing services within the current health care delivery system and these adversities, however nuanced, warrant a more detailed exploration. Departing from the understanding Francophone participants within this study experienced their cancer illnesses within the specific cultural, linguistic and geographical contexts described above, the impact of risk, uncertainty and resilience will now be explored in reference to the impact of these men's disease experiences on their quality of life.

2.1.3 Quality of Life

Once diagnosed with prostate cancer, most men adjust to the fact that they have a potentially serious illness – one that may pose a threat to their health, life and quality of life (Lee & Penson, 2002). Despite the growing interest in quality of life within oncological research (Kim et al., 2014; Lebre et al., 2014; Serda I Ferrer, Del Valle, & Marcos-Gragera, 2014; Song, Ji, & Nielsen, 2014), there is still no consensus on the definition of quality of life. In fact, Moons and colleagues (2006) have presented a review on eight different conceptualizations of quality of life; each diverging in terms of epistemological assumptions and other major philosophical beliefs. According to their review, the definition of “quality of life” has ranged from an indicator of “functional status”, to “symptom burden”, to “life satisfaction” (Moons, Budts, & De Geest, 2006). In fact, quality of life is often used as an umbrella term to describe a number of physical and psychological variables such as health status and physical functioning, psychological well-being, spiritual connectedness, perceptions, social well-being, overall happiness and satisfaction, lifestyle, symptomology, etc (Dijkers, 2007; Ferrans, 2007; Hamoen, De Rooij, Witjes, Barentsz, & Rovers, 2014; Milton, 2013;). Quality of life has become an important parameter for evaluating patients' evaluation of the quality and outcome of various treatment modalities (Ferrer et al., 2013; Van den Bergh et al., 2014). This is especially true in cases for prostate cancer patients for whom quality of life has become a critical measure in the absence of a curable prognosis (Doyle-Lindrud, 2007; Gerbershagen et al., 2008; Kohler et al., 2014; Phillips & Currow, 2010).

Within the present study, a move past an objectivist biomedical definition of quality of life (e.g. functional status or disease burden) to a more subjective understanding of participants' illness experiences will occur. In fact, this study recognized that only the participants themselves

could truly acknowledge what quality of life means to them. Within a particular context of geographic distribution and/or geographic isolation, as members of a linguistic minority population who are forced to navigate a health care system that for many had been foreign to them up until the time of their initial diagnosis, it was recognized that their conceptualization of quality of life would be embedded within the social, cultural and geographical fabric of their lives. In fact, allowing a more subjective understanding of the concept of quality of life within the framework of this study was of particular importance since it facilitated a more holistic account of their disease trajectory and shed light on the various mechanisms and strategies they utilized to define, understand and conceptualize their own illness experiences. More so, the socially constructed understanding of quality of life derived from participants' perspectives employed herein, recognizes the influence of their cultural meaning systems, personal values and linguistic preferences on their interpretation of their overall disease experience and its ultimate impact on their post-treatment quality of life.

2.1.2 Resilience

The concept of resilience is central within the parameters of this study. The development of the concept of resilience can be best understood as a realignment of its own conceptualization; or, as a particular “paradigm shift” (Kuhn, 1962) within its own understanding. Historically, resilience was recognized as a static individualistic personality trait. As such, a person's resilience was most often linked directly to his or her “physical illness” (within the biomedical model) or “mental illness” (within the psychological model of Freudian psychotherapy) (Rutter, 2012). However, as this positivist approach to the understanding of resilience was no longer supported by the mounting evidence demonstrating an individual's capacity to overcome a perceived negative personal circumstance and recover from a stressful event; the concept itself was “shifted” in order to adapt to a broadened understanding of the phenomena (Rutter, 2012).

According to Reich and colleagues (2010), the resilience paradigm more adequately conceptualizes the dynamic adaptation that occurs in response to a particular stressor (such as a diagnosis of prostate cancer), rather than the mere absence of the disease and as such, resilience should be understood as “a distinct process, independent of illness dimensions” that should be “studied in its own right in terms of antecedent, process and outcome variables” (Reich et al., 2010, p. xii). In other words, any conceptualization of resilience requires an understanding of it

as a dynamic, interactional and inferential concept because it refers to what happens before, during and following conditions that threaten the homeostasis of the individual. As such, understanding the capacity of Francophone prostate cancer patients to access resources to maintain and sustain their ongoing post-treatment well-being, while also taking into account the contextualized complexities surrounding access and distribution of these shared resources within a culturally and socially negotiated manner, is central to the development of a deeper understanding of the effects of this disease on these men's perceptions of their overall quality of life (Ungar, 2012; Ungar et al., 2007;).

Within this study, resilience is therefore defined as the “capacity of individuals to navigate their way to resources that sustain well-being, the capacity of individuals’ physical and social ecologies to provide these resources and the capacity of individuals and their families and communities to negotiate culturally meaningful ways for resources to be shared” (Ungar, 2008, p. 22-23). Resilience will also be viewed as a critical factor of influence in participants’ illness trajectories since patients’ cultural beliefs and social practices will also be understood as key factors influencing how participants’ interpreted their experiences with prostate cancer. In essence, a more comprehensive approach to the study of resilience among prostate cancer patients is necessary in order to better understand how participants’ cultural beliefs and social practices influence their interpretation of risk (primarily at time of diagnosis and during their treatment selection period) and their assessment of their post-treatment quality of life.

2.3 Chapter Summary

This chapter presented the social constructivism as the theoretical framework guiding this study. In addition, this chapter presented the conceptual model steering this work, while also highlighting the fluid and culturally abstracted notions of quality of life and resilience, as defined within the structure of this study. Specific attention was placed on emphasizing the fluid and dynamic nature of men's personal understandings of their illness experiences and recognized these as both created of and influenced by the unique circumstances imposed upon them by virtue of their linguistic minority standing within the northern and rural context of their geographic residence. In the following chapter, readers will be presented a detailed account of the qualitative research methodology applied in this study.

CHAPTER 3: RESEARCH METHODOLOGY

A qualitative methodology was utilized for this present study as a method for exploring and analyzing the unique social and contextualized illness experiences of Francophone prostate cancer patients from Northeastern Ontario. Since a qualitative methodology allows for a more comprehensive understanding of each participant's realities, this approach appealed to the social constructivist paradigm that centered the study. More so, in contrast to quantitative methodologies, qualitative research necessitates face-to-face interactions with study participants which inevitably establishes an interpersonal rapport between the parties. Evidently, as a female researcher undertaking the study of men's prostate cancer experiences, a disease that impacts the core of men's health, sexuality and masculinity; participants had to feel comfortable with me and invested in the project, in order to reveal their stories in an open and candid manner. The interpersonal dynamic fostered within the parameters of qualitative methodologies allowed participants a confidential manner in which they could share a more detailed account of their illness journeys. The intent of this study was not to generalize the findings to other populations but to describe and articulate a theoretical dimension of participants' experiences in order to begin reflection and dialogue on the unique nature of Francophone prostate cancer patients' illness encounters.

3.1 Study Design: Grounded Theory Approach

The pioneering works of Glaser and Strauss (1967) and Strauss and Corbin (1990) introduced me to the broad parameters of grounded theory. My initial penchant towards this framework was further reinforced upon reading the works of Dr. Kathy Charmaz (2006), a grounded theorist who conducts her research from a constructivist perspective. Through her work, I came to understand that my approach to the study of the social construction of Francophone prostate cancer patients' illness experiences would parallel Charmaz's notion of constructivism; whereby multiple realities co-exist and knowledge is created through fluid, interactive processes between the researcher and the participants. Constructivists assume that both their data and analyses are social constructions that reflect their production, and as such, recognize that "any analysis is contextually situated in time, place, culture and situation"

(Charmaz, 2006, p. 131). This view thus afforded this study to delve more deeply into the unique views and subjective meanings that its participants attributed to their personal experiences of illness within the Northern community context.

Grounded theory approaches are often used when no dominant theory exists to explain how individuals are experiencing a particular phenomenon (Creswell, 2013). Since the manner in which Francophone prostate cancer patients construct and reconstruct their lives following their diagnosis has not been fully explored, it was believed that a qualitative grounded theory approach would result in the identification of primary phenomena and related categories; thus leading to a better theoretical understanding of the strategies these men utilized when faced with this disease. As affirmed by Smith (1997), there is much benefit to the use of a qualitative methodology that is able to explicate a particular phenomenon, such as the experience of prostate cancer, from the perspective of the participants actually experiencing the problem in order to uncover perceptions of their own social world (Smith & Biley, 1997).

Using a grounded theory approach allowed me to not only to discover circumstances and processes (e.g. salient issues related to the experience of prostate cancer, such as availability of services in one's primary language or the use of informal social supports), but to determine how individuals reacted to changing conditions and the apparent consequences of their decisions and behaviours (Corbin & Strauss, 2008; Lee & Penson, 2002). Notwithstanding its popularity in a variety of social science and health disciplines (e.g. sociology, nursing, education, and gender studies, etc.), there continues to be much debate regarding what fundamentally constitutes grounded theory.

Pioneered by Glaser and Strauss (1967), the defining components of grounded theory consist of: 1) simultaneous involvement in data collection and analysis, 2) constructing analytical codes and categories from the collected data, 3) using a constant comparative method (which involves making comparisons during each stage of the analysis and, 4) advancing theory development during each step of data collection and analysis. However, many current researchers are moving away from such a positivist approach to conducting grounded theory and are instead adopting and adapting these guidelines in order to meet the unique requirements of their own respective studies (Charmaz, 2006).

As previously mentioned, the method used in the present study was the constructivist approach put forth by Charmaz (Charmaz, 2006; Charmaz & Bryant, 2008) which recognizes grounded theory's roots in symbolic interactionism (Blumer, 1969). As previously highlighted, symbolic interactionism focuses research on the symbolic nature of human interactions and concedes that individuals engage in social interactions to which they bring their own definitions, meanings, and interpretations (Crooks, 2001). Charmaz's constructivist view of grounded theory emphasizes the importance of understanding that which is being studied, and more significantly, favours theoretical discernment over elucidatory generalizations (Charmaz & Bryant, 2008). Several authors have promoted the adoption of key strategies from earlier versions of grounded theory method devoid of their positivist underpinnings (Bryant & Charmaz, 2007; Charmaz, 2011; Clarke, 2005). Constructivist grounded theory, as articulated by Bryant and Charmaz (Bryant & Charmaz, 2007) advocates a relativistic approach to research and "emphasizes: (a) the social conditions of the research situation; (b) the researcher's perspectives, positions and practices; (c) the researcher's participation in the construction of data; and (d) the social construction of research acts, as well as participants' worlds" (Charmaz & Bryant, 2008, p. 376). This represents an opposing view to the strict principles of grounded theory, as represented by Glaser and Strauss' original version (1967) and Corbin and Strauss' contemporary version (2008). In Charmaz' opinion, these positivist frameworks attempted to erase the part of the researcher, the social context of the research, and the interaction between the researcher and the participants researched (Charmaz, 2006).

In the present study, I adopted Charmaz' position and approached my inquiry from a collaborative and interpretive stance in order to impart an increased theoretical and social sensitivity to the study of Francophone prostate cancer patients' experiences and to highlight patterns and connections that were not previously considered.

3.2 Selection and Recruitment of Participants

The tenets of grounded theory incorporate a sampling model that is based on theoretical assumptions. In other words, the selection of participants focuses on theoretical significance, rather than on reaching a certain number of participants (Charmaz, 2006). In keeping with grounded theory methodology, initial sampling was used to determine the first few interviews and then purposeful sampling guided the remainder of the data collection (Charmaz, 2006;

Licqurish & Seibold, 2011). A more detailed look at the sampling techniques used in this study will now be presented.

3.2.1 Sampling

Initial sampling is a methodological process that involves the establishment of sampling criteria for people, cases, situations and/or settings prior to the researcher entering the field and thus acting as a departure point in a grounded theory study (Charmaz, 2006). The initial sampling criteria that were first used for this study were: i) participants self-identified as a Francophone; ii) participants were between 12-60 months post-diagnosis; iii) participants resided in Northeastern Ontario at their time of diagnosis and were treated for their disease in Northeastern Ontario; iv) participants were over 18 years of age; and, v) participants were willing to participate, able to recall, and able to articulate their experiences with prostate cancer in either the French or English language.

These initial sampling criteria were reviewed and after careful consideration and discussions with my thesis supervisor, the criterion of post-diagnosis time was modified by removing the limit on post-diagnosis time thus expanding the potential participant pool to anyone who was at least 12 months post-diagnosis. In addition, the criterion of being “treated for their disease in Northeastern Ontario” was also removed since it did not reflect the reality of circumstances that men from northern communities faced when dealing with a diagnosis of prostate cancer. More specifically, patients from Northeastern Ontario, especially those living in more northern and rural communities, were often forced to travel long distances outside of their region in order to access and obtain specialized health services. In fact, many participants from this study lived in communities that did not even offer primary or secondary health care services.

Theoretical sampling is another emergent and continuous aspect of the research process that recognizes that neither the composition nor the required number of research participants can be known in advance (Charmaz, 2006; Corbin & Strauss, 2008). Strauss and Corbin (1998) defined theoretical sampling as “sampling on the basis of emerging concepts, with the aim being to explore the dimensional range or varied conditions along which the properties of concepts vary” (Strauss & Corbin, 1998, p. 73). The terms purposeful sampling and theoretical sampling are often used interchangeably (Lincoln & Guba, 1985). Within this strategy, the researcher

follows the leads discovered in the initial stages of interviewing and data analysis by seeking the relevant information in subsequent interviewing and data analysis. The researcher pursues information in a theoretical sampling process in order “to elaborate and refine categories” (Charmaz, 2006, p. 96) for the emergent theory. When no new features emerge, the categories are said to have become saturated. This process of data “saturation” is the primary goal of theoretical sampling; which is focused on achieving conceptual and theoretical development rather than on increasing statistical generalizability of the results or on representing a particular population (Charmaz, 2006). However, as stated by Corbin and Strauss “total saturation (complete development) is probably never achieved” (Corbin & Strauss, 2008, p. 149). Nevertheless, sufficient sampling can be said to have occurred when categories demonstrate adequate depth and breadth of insight, and there is a clear understanding of their relationships in regards to other categories (Corbin & Strauss, 2008).

In the present study, theoretical sampling was employed to ensure that men with a wide variety of experiences (e.g., based on geographic location, cultural background, type of treatment received, age and status at time of diagnosis) were interviewed. This sampling method is based on the idea that known, suspected, or reported conditions (e.g., delayed time of diagnosis, barriers to accessing treatment in one’s primary language, or possible isolation due to lack of medical understanding) are used to identify and select topics or areas for further review (Corbin & Strauss, 2008).

A snowball sampling technique was also incorporated into the study design protocol. Snowball sampling involves asking participants already interviewed for information needed to locate other individuals within the same population (Babbie, 2009). Consistent with theoretical sampling, men referred using this snowball technique were contacted in order to determine if they could add critical insight in relation to emerging categories and themes.

3.2.2 Participant Recruitment

My recruitment strategy targeted prostate cancer patients within Northeastern Ontario. In an effort to highlight the purpose and credibility of this project within the targeted populations and in an attempt to accelerate my recruitment initiatives at the grassroots level, I contacted the offices of the Honourable Jack Layton, then Leader of the Official Opposition, New Democratic

Party of Canada for feedback on my proposal. Upon review of my documentation, Mr. Layton provided me with an official endorsement (see Appendix A) which I included in some of my promotional and recruitment packages. Specifically, in an attempt to market this research project as a non-threatening conversation between two people, I developed a marketing campaign that was branded as “Conversations over Coffee/ Café et Conversations” (see Appendices B & C) and created several promotional items (e.g. cards, pamphlets and brochures) for distribution.

Using the visual imagery of having a candid conversation over coffee with the slogan of *“Sharing your Prostate Cancer Experience Can Help the Next Guy! / En partageant votre histoire, vous pourriez aider le prochain!”* I wanted to convey the informal, non-threatening nature of the participation requirements for this project. These promotional materials (in conformity with the research project) were displayed in 22 stores, 12 Tim Horton’s coffee shops, two community centres, 10 medical doctors’ offices and three hospitals throughout Northeastern Ontario⁴. However, posting flyers at Health Sciences North in Sudbury (including the Northeast Cancer Centre of Health Sciences North), the North Bay Regional Health Centre and the Timmins and District Hospital) proved problematic since these institutions enforced advertising policies that required pre-approval from internal ethics boards. Given the limited time available for the data collection phase of this study, flyers were only placed in locations that were approved upon first contact.

In June 2011, I recruited friends and family members (e.g. my two parents and three friends) to attend the “Prostate Cancer Ride for Dad” motorcycle ride event, a fundraising initiative organized by the Northeastern Cancer Foundation in Sudbury, Ontario. Understanding that this event would host an aggregate of potential participants, we spent the morning speaking with riders and participants about my research and handed out over 100 free Tim Horton’s coffee cards (value: \$2.00 each) with my research and contact information printed on them. While all the men and women approached at the event were very forthcoming and enthusiastic about my

⁴ Promotional materials were displayed in 22 stores (7 in Greater Sudbury, 3 in North Bay, 2 in Sturgeon Falls, 2 in Timmins, 5 in Hearst, 3 in Kapuskasing), 12 Tim Horton’s coffee shops (5 in Greater Sudbury, 2 in North Bay, 1 in Sturgeon Falls, 2 in Timmins, 1 in Hearst, 1 in Kapuskasing), 2 community centres (1 in Sudbury and 1 in Hearst), 10 medical doctors’ offices (7 in Greater Sudbury, 1 in North Bay, 1 in Timmins, 1 in Hearst) and 3 hospitals (West Nipissing General Hospital, Hôpital Notre-Dame de Hearst and Sensenbrenner Hospital in Kapuskasing).

research (some going so far as thanking me for caring enough to conduct this research), only two men contacted me to express interest in participating. Unfortunately, these men did not meet my initial selection criteria.

Another strategy, that later proved to be the most useful, was getting in contact with the chapter presidents of the four Prostate Cancer Support groups in Northeastern Ontario (in Hearst, North Bay, Kapuskasing and Timmins). After obtaining their information via the Prostate Cancer Care Network website, I emailed or called (depending on available contact information) each of the four group leaders individually and then mailed them an information package containing letters of introduction, research brochures, posters and coffee cards. Upon receipt of the information packages, two of the four leaders contacted me and offered their assistance in the recruitment of participants⁵. While the third group leader never returned my calls, in time, the fourth group leader became the most helpful contact in my study. Having been pre-approached about my project by a member in his community prior to my initial contact, the president of the fourth Northeastern Ontario prostate cancer support group I contacted was already familiar with my project and in effect, with me. Wanting to be of assistance to me in any way he could, this group leader contacted each member of his support group and by the time he and I connected over the phone three weeks later, he had compiled a list of 32 potential participants who had agreed to let me contact them directly; ultimately resulting in 16 affirmative responses. Thus, this grassroots recruitment strategy proved to be the most useful; most likely due to the positive endorsement provided by the support group president who increased the perception of the study's credibility to potential participants.

As interviews were carried out, further recruitment by networking was attempted. This approach was used by three of the participants who informed me of other men who had prostate cancer diagnoses and resulted in an additional three participants. The final three participants of this present study were recruited through various personal connections, via work colleagues, family, friends and other acquaintances that referred participants to my study. The total number of participants was twenty two. Although participants' wives were not recruited within the

⁵ It is impossible for me to provide the reader with additional details related to which specific support groups participated in this study as it would compromise participant confidentiality.

framework of this study, nor were they systematically present during the data collection phase, four participants' spouses were in attendance during the interviews. Even though their presence could have created a degree of interference during the interview, spousal participation offered a level of support these particular participants wanted in order to help them feel more comfortable discussing their illness experiences with me. The supportive role of the spouse of partner in men's health interactions has been widely discussed within the research literature (Badr & Krebs, 2012; Droupy, Al Said, Lechevallier, Colson, & Giuliano, 2013; Galbraith, Fink, & Wilkins, 2011; Lafaye et al., 2014) and their presence in this particular study was regarded as extremely valuable since they contributed important insights vis a vis the realities that prostate cancer poses on the couple.

3.3 Ethical Considerations

Approval to conduct this research study was obtained from the Research Ethics Board (REB File Number: 2011-04-08) at Laurentian University in Sudbury, Ontario (Appendix D). Prior to being interviewed, each participant received a letter of introduction (see Appendix E) describing the nature of the study and an informed consent form (see Appendix F) reaffirming that their participation was entirely voluntary and that they could withdraw at any time and without consequence. Participants also agreed to be digitally audio-recorded during the interview and were given assurance that confidentiality would be maintained throughout this study and that their names would not be associated with any information they provided. Each participant was given a code number, and codes were assigned and used within all transcripts and reports. In addition, the names used to represent study participants within this manuscript are pseudonyms; which were assigned alphabetically and chronologically. For example, "Alex" was the first man interviewed and "Bob" the second. The digital audio-recorded interviews were transcribed verbatim and documents were password protected on a secure laptop, and the printed transcripts were kept in a locked filing cabinet in the researcher's office and will be destroyed after seven years, in accordance with accepted research criteria at Laurentian University. All audio recordings will be destroyed upon completion of the dissertation.

3.4 Potential Risks and Benefits

While there were no serious anticipated risks associated with participation in this research study, special considerations were made to ensure that the participants had the time they needed in order to complete the interview; allowing for breaks or stopping the interview at any point requested. Interviews took place either in a private location adjacent to a private washroom (frequent urination is a common side-effect of many prostate cancer treatments) or in participants' homes. All participants were provided with the names and contact information of the Manager of Health & Counselling Services at Laurentian University and of a Sudbury-based Family Physician specializing in psychotherapy, who had both agreed to make themselves available to anyone (e.g. participants and/or accompanying spouses) requiring further support or counselling as a result of their participation in this study. Participants were encouraged to discuss their feelings openly and were given as much time as they needed in order to process their experiences.

3.5 Interview Process and Data Collection

Between June 28, 2011 and October 3, 2011, 22 face-to-face, in-depth interviews were conducted with Francophone men from eight different communities throughout Northeastern Ontario⁶. Six of the eight participant communities were considered “rural” at the time of the data collection, based on the Ministry of Health and Long-Term Care’s *Rural Ontario Index*. As previously mentioned, this definition of rurality considers three primary factors, namely, extended travel time to an advanced referral centre, extended travel time to a primary referral centre, and population (count and density) (Ministry of Health and Long-Term Care, 2010). In addition, rurality was also conceptually recognized as belonging to continuum rather than a recognized an absolute abstract within geographic catchment areas within Northeastern Ontario that possessed a larger population of Francophones; many being 1st generation Francophones. Within this geographic and linguistic context, many of the study’s participants were recognized

⁶ Communities included: Greater Sudbury (Sudbury, Azilda, Hanmer & Garson), Hallebourg, Hearst, Iroquois Falls, Kapuskasing, North Bay, Smooth Rock Falls and Val Côté.

as living in underserved communities which contributed to their unique stance in reference to their illness experiences.

In-depth interviews, according to Charmaz (2006) are directed conversations and by nature a detailed “exploration of a particular topic or experience (...) eliciting each participant’s interpretation of his or her [own] experience” (Charmaz, 2006, p. 25). I conducted all interviews, in the participant’s home community, at the time and location of their choosing (e.g. in the participant’s home, my office or a reserved meeting room at the local hospital). In addition, since this study occurred in a cross-cultural setting deliberate steps were taken in order to preserve the qualitative vigour within the research methodology while also maintaining an increased level of cultural sensitivity to the population of interest. As stated by Regmi and colleagues (2010), good qualitative cross-cultural research and analysis is not an easy task as it involves knowledge of different approaches, techniques and command of the appropriate languages (Regmi, Naidoo, & Pilkington, 2010). Being fluently bilingual in French and in English, I was able to conduct each interview in the language of preference of the participant and was able to ensure that all the study material was presented in either language. While most participants chose to conduct the interview in French, some interviews were conducted in a mix of both languages.

An informed consent form (Appendix F) was provided and reviewed in detail with each participant prior to obtaining their signature. A copy of the consent form was given to each participant for their records. The tone of the interviews was conversational and naturally flowing with each lasting between approximately 40 minutes to two hours. An interview guide containing several broad, open-ended questions were developed in order to focus the interview and to ensure detailed discussions related to the initial themes of inquiry of this study; 1) quality of life following a diagnosis of and treatment for prostate cancer; 2) the availability and access of health care services within the patient’s preferred language; 3) the impact of culture and geographic placement on their experience as a prostate cancer patient (see Appendix G). However, consistent with the principles of grounded theory, the interview guide was iterative, and framework. For example, after the first few interviews, the lack of information on access and exposure to primary care services emerged in the analysis. Therefore, questions were added related to participants’ prior encounters with serious illness as well as their previous exposure to

health care services (personally or by venue of a close family member or friend) in order to better understand the overall context in which their diagnosis of prostate cancer was experienced.

As previously mentioned, 22 men participated in the research project. It is important to note that all participants were prostate cancer survivors; to the extent that they received their diagnosis of the disease, were treated for it and at the time of the study, had survived. As such, this participant group does not necessarily reflect the experiences of men who succumbed to the disease; since we will never know their particular realities. In addition, it is important to note that during four of the interviews held, participants' wives were present and each completed informed consent forms. Although these women were not the targeted population of the study, their input and insight were recognized and captured as valuable data in this research.

All participants were asked to complete a comprehensive socio-demographic questionnaire focusing on personal information, health information and language preference information (see Appendix H). This questionnaire was essential for the collection of pertinent participant information which was used to obtain a comprehensive description of the population investigated in this study. Based on this data, it can be revealed that the average age of participants was 71.46 years with a range between 51 and 89 years. In addition, most participants in the study were married ($n = 19$) and only three participants were divorced. Five participants reported having completed some elementary school education, six had elementary, three had some high school, five had high school, two had university, and one had completed graduate studies. Nine participants reported annual incomes of \$40,000 - \$59,999; eight reported between \$60,000 - \$79,999 and two reported between \$80,000 - \$99,999. Three participants did not report their income. All participants were born in Canada and had been living in Northeastern Ontario for a mean of 67.3 years at the time of the study. On average, participants were diagnosed with prostate cancer 8.6 years prior to participation in the study (with a range of two-18 years). Most participants ($n=16$) received radical prostatectomies as their first line of treatment against the disease, while three received radiation therapy; one received brachytherapy and two received hormone therapy. Three of the participants who received radical prostatectomies later received additional treatments (radiation or hormonal therapy), and one participant who received hormonal therapy as his first line of treatment later received additional radiation therapy. Please

refer to Appendix I for details on the frequency distributions of participants based on selected socio-demographic variables.

All interviews were digitally audio-recorded using two separate digital audio recorders and were transcribed verbatim in the language of the interview. I transcribed the first several interviews to allow for immersion in the data. All subsequent interviews were transcribed by two university students hired for the duration of the research project. All interviews were listened to by the interviewer in their entirety to uncover areas of uncertainty or ambiguity, to ensure the accuracy of the transcriptions, and to review the quality of the information obtained from the interviews (Patton, 1999; Patton, 1990).

In addition, upon completion of each interview, I completed a “Post-Interview Report” (Appendix J). This report included information on the date, time and location of the interview; the method of initial contact with the interviewee; details on the progression of the interview in terms of the social climate, strengths of the interview, themes that emerged or were omitted as well as privileged information provided to the interviewer. For example, one respondent requested that the audio-recorders be turned off in order to address his perceived lack of confidence and satisfaction with his family physician. Although the respondent understood the confidential nature of our interview, he could not bring himself to discuss this topic “on the record.” The post-interview report also captured information on the interviewer’s perceptions of the participants such as body language displayed, attitude during the interview and where applicable, their home environment.

Finally, throughout the duration of the study, I kept a reflective journal that captured my observations during the data collection process, personal entries, audit trail details as well as other field notes not previously obtained in the post-interview reports (e.g. details related to wives’ presence during interviews). I also took notes during the course of the interview on key points made by participants that needed to be revisited during the interview, as well as contradictions that emerged during our discussions. Topics that we obviously omitted from the interview discussion (e.g. consequences of treatment on physical and sexual health) were also identified. Time to debrief after each interview was included in the research protocol because of the importance of providing as much contextual information as possible on each interview in

order to aid in the future analysis of this data (Patton, 1990). However, the realities of conducting such an extensive research project with participants in 8 different communities across Northeastern Ontario imposed certain adjustments to the research protocol. For example, during the four trips I made to northern rural communities (up to 600 kilometres away), I scheduled multiple interviews each day in order to maximize the number of participants I could reach during my three or four-day visits. This led to long interview days that on occasion superseded my planned time for self-reflection. During these busy interview days, I would ensure to record my initial thoughts immediately following each interview in the post-interview report, and then return to these notes for more comprehensive reflections within the days following the interview. This element of reflexivity was an important step in my research process since it helped identify some of the intersubjective elements of influence on my data collection (e.g. the presence of wives or having multiple interruptions during the interview, or participants' discomfort when discussing particular topics, etc.). According to Corbin and Strauss (2008), this reflexivity increases the integrity and the trustworthiness of the data collected by offering a better representation of the phenomena under question (Corbin & Strauss, 2008).

3.6 Data Analysis

The data analysis for this study followed the principles of grounded theory. Grounded theory uses an iterative approach, which involves cycles of simultaneous data collection and analysis, in which the results of the ongoing data analysis inform the subsequent data collection (Charmaz, 2006). Coding, memo writing, theoretical sampling (discussed above), theoretical sensitivity and constant comparison methods were integral to the process of data collection and analysis in this study. The use of each of these techniques is discussed in more detail in the following sections.

3.6.1 Coding

Qualitative coding is the process of defining, summarizing and categorizing the data collected (Charmaz, 2006). Consistent with the grounded theory approach, the data collected in this study were analyzed using a modified version of the constant comparative method pioneered by Glaser and Strauss (1967) and later adapted by Charmaz (2006). Upon the completion of my data collection phase, I engaged in a theoretical analysis of the data by first conducting a

thematic analysis of the data (e.g. line-by-line conceptual coding), followed by a more focused theoretical coding (Charmaz, 2006). More specifically, during these initial stages, I manually coded the data line-by-line in order to identify, name, and describe phenomena found in the text and conceptually matched them to the relevant themes found within the interview guide. I also kept track of any emerging ideas that could be further explored during subsequent interviews. Simultaneous collection and analysis of data allowed for a comprehensive examination of the thematic underpinnings of the interview guide with an iterative thematic emergence of new areas for further questioning during future participant interviews.

Upon completion of the initial coding, focused coding was conducted. Focused coding thus involved vetting through the large amount of data captured during initial coding and then grouping relevant codes together under appropriately conceptualized categories that lead to the emergence of new categories. These focused codes were therefore more directed, selective and conceptual than those previously identified (Charmaz, 2006).

Focused coding is a prelude to theoretical coding, which involves classifying and grouping the significant statements into meaning units (conceptual categories); interpreting the data through textural (what happened) and structural (how the phenomenon was experienced) descriptions in order to describe how these codes relate to each other in an overarching explanatory theory (Creswell, 2007). This focused analysis of both the concepts and the themes identified was an integrative process whereby the relationships between the categories, the concepts and each other, were explored in order to better crystallize participants' experiences within an interpretive framework able to capture the nuances of those experiences.

Once initial, focused and theoretical coding were completed, a dynamic analysis of each participant's account was conducted, resulting in individual schematics or diagrams of each interview. These diagrams provided a visual representation of the concepts and themes that emerged during the interview. Charmaz (2006) supports the use of diagramming since it enables the researcher to identify the relative power, scope, direction and relationships between each concept and theme. A comparative (between the interviews) analysis was then conducted in order to ensure the richness of the individual accounts was captured and collated to contextualized commonalities among all participants (Creswell, 2007).

3.6.2 Constant Comparison

Constant comparison is the staple feature of grounded theory methodology (Corbin & Strauss, 2008). Originally developed for use in the grounded theory methodology of Glaser and Strauss, this inductive method of analysis involves taking one piece of data (one interview, one statement, one theme) and comparing it with all others that may be similar or different in order to develop an understanding of the possible relationships between various pieces of data (Glaser, 1965). In this present study, the ongoing comparison between codes, categories and individual interviews continued until each new interview or account had been compared with the others, and subsequently occurred on a macro-linguistic level to increase the conceptual understanding of the commonalities and variations among the Francophone participants. In other words, the similarities and nuances found within the conceptual, thematic and theoretical codes among Francophone participant accounts were constantly reviewed in terms of the breadth and depth of their experiences as well as in light of the potential distinctions in order to capture a culturally driven understanding of said experiences.

3.6.3 Memo Writing

Memo writing is also an essential step between the data collection phase and the draft thesis writing phase within the grounded theory methodology. According to Glaser (1978), memo writing consists of the theoretical write-up of ideas about codes and their relationships as they occur (Glaser & Strauss, 1967). Theoretical memo writing is a crucial component within the grounded theory process because it compels the researcher to critically analyze and code data early in the process of theory generation (Charmaz, 2006). Memos capture the researcher's analytical process and reflect the inner dialogue one is having with the collected material at particular points in time (Charmaz, 2006). Memos build researcher reflexivity into the process; thus adding to the study's credibility by clearly documenting each step taken within the data analysis phase; from collecting the raw data to making final interpretations.

In this present study, memos were written in a variety of ways. I began memoing immediately following my first interview. Memos were captured in my reflective journal or in the post-interview report and reflected my thoughts and impressions from each individual interview. These memos provided me a space to discuss emerging ideas, codes or concepts that

could be integrated into upcoming interviews. When emerging codes were raised to the level of a category, I created a memo describing the category; the codes contained within that particular category, illustrative quotes that reflected that category, and further ideas on which to follow-up to ensure theoretical saturation of each category. This process continued until I had no new elements to add to a particular category. These memos were eventually sorted and integrated to create the first draft of the findings.

3.6.4 Theoretical Sensitivity

Theoretical sensitivity, as described by Glaser (1978), refers to the researcher's knowledge, understanding and skill; which foster one's generation of categories and properties and increases one's ability to relate them into hypotheses, and to further integrate the hypotheses according to emergent theoretical codes. According to Charmaz (2006), to gain theoretical sensitivity, the researcher must approach the study of their data from various vantage points and "reach down to the fundamentals, up to the abstractions and probe into experience" (Charmaz, 2006, p. 135). It is critical to collect and analyze data at the same time since this continuous interaction with the data increases one's insight thus allowing for multiple understandings of concepts and meanings.

Theoretical sensitivity was obtained in this study by a thorough review of the relevant literature and by using the constant comparative method throughout the data collection process. The constant comparative method (as previously discussed) enhances theoretical sensitivity by stimulating thinking about incidents, concepts, categories and their properties (Jeon, 2004). Theoretical sensitivity was also obtained during discussions with my thesis supervisor, colleagues within and outside the medical school environment and members of the larger health care community.

3.7 Criteria for Evaluating Qualitative Research

There is a great deal of debate surrounding the evaluation of qualitative research (Anderson, 2010; de Laine, 2000; Jootun, McGhee, & Marland, 2009). While there is general agreement among qualitative researchers regarding the importance of critically evaluating research through the application of criteria; the debate remains in relation to which criteria should be used when conducting this assessment (Willig, 2001). However, there is consensus

among researchers that comprehensive qualitative research involves the subjective interpretation of the information collected within a specific time, place and context, and as such, aims for the interpretation of socially and culturally-specific findings rather than the discovery of generalizable results to a broader population (Creswell, 2013).

Lincoln and Guba (1985) embrace a naturalistic approach to research evaluation and speak of credibility, transferability, dependability and comparability when assessing qualitative work. In the following sections, we will focus on these particular criteria and will outline the various steps taken in the present study to promote the rigour and the quality of this research study.

3.7.1 Member Checking

According to Charmaz (2006), credibility is an evaluation of whether or not “the research has achieved intimate familiarity with the setting or topic; the data sufficient to merit claims (considering the range, number and depth of observations contained in the data); systematic comparisons between observations and between categories; strong logical links between the gathered data and the argument and analysis; and provision of enough evidence to allow the reader to independently assess and agree with the presented claims” (Charmaz, 2006, p. 182). In the present study, participants guided the inquiry process (e.g. informally through their questions during- and feedback post- interview) and through these interactions the interview guide and the preliminary codes generated from the data analysis were revised. I, upon completion of my preliminary analysis, several members of my participant pool, who had previously indicated their interest in facilitating this process, were contacted in order to obtain their comments and feedback on my initial interpretations of the data. Two participants agreed to review the material and provided me with valuable insights regarding my interpretation and analysis of their experiences. This form of member checking is consistent with the tenets of constructivist grounded theory as it promotes the shared interactions of the researcher and the researched in the ongoing co-creation of culturally, socially and historically specific meanings and experiences (Charmaz, 2006). Detailed notes and memos were captured in my reflective journal and on the post-interview reports in order to adequately describe the interpretive analysis conducted; in light of my own personal biases and theoretical assumptions as well as the extant literature on the constructed experiences of prostate cancer patients.

3.7.2 Dependability

Lincoln and Guba (1985) equate dependability with reliability of the research process. The concept of dependability encourages researchers to provide an extensive audit trail (the documentation of data, methods and decisions about the research) which can be laid open to external scrutiny. This is conducted in order to demonstrate the historical, situational and social contexts are influencing the collection and interpretation of the findings; rather than to seek to be consistent or to gain consistent results. As described by Finlay (2006), “qualitative research takes the position that situations can never be accurately replicated (...) [and] what emerges is contingent on the researcher’s approach and the particular interviewer-participant relationship and context” (Finlay, 2006, p. 321). In keeping with the tenets of constructivist grounded theory methodology, theoretical sampling, constant comparison method and memoing were employed. In addition, all evaluations and decisions made during the duration of the study were documented as a means to create openness and transparency of the research process; while also being cognizant of the need to protect the anonymity of the participants.

3.7.3 Confirmability

As acknowledged by Lincoln and Guba (1985), confirmability acknowledges inevitable researcher biases and promotes self-awareness to enhance the neutrality of the research process allowing more freedom for the co-creation of knowledge. Key to this process within my study were repeat meetings with my thesis supervisor who, acting in the capacity of a peer-debriefer, raised and discussed issues and questions regarding the creation and formation of conceptual categories and the meaning given to the interpretation of the relationships between concepts. In addition, from the very beginning, I kept a detailed decision trail and comprehensive reflective journal outlining all procedural or contextual issues that were experienced during the course of this study.

3.8 Chapter Summary

Chapter 3 introduced grounded theory as the methodology used for this present study. The tenets of grounded theory were explained, a description of Charmaz’ constructivist grounded theory was provided and the assumptions guiding this present study were discussed. The interview process and data collection procedures were also outlined. Lastly, the data analysis

plan as well as criteria for evaluating research rigour in qualitative studies were identified and discussed. The following chapter will present the first part of this study's results and will focus on participants' prostate cancer experiences from the time of their initial diagnosis to the process in which they engaged in in order to select and receive their treatment. Chapter 4 will also highlight the important role of supports in this decision-making process.

CHAPTER 4: PARTICIPANTS' EXPERIENCES WITH PROSTATE CANCER

Prostate cancer is a quintessential man's disease, linked to the very core of the male identity. Each lived encounter with prostate cancer is as unique as the person experiencing it. In the present study, men diagnosed and treated for the disease in Northeastern Ontario described their own experiences. Despite initial fears that the men recruited within the parameters of this study would be hesitant to open up about such personal and intimate experiences, the accounts that will now be discussed demonstrate that the opposite occurred. Within a dynamic of trust and respect, participants acknowledged the impact of prostate cancer on their well-being and quality of life. Some conceded that they continue to struggle with the negative consequences of their treatment decisions while others recognized an even greater sense of resilience and appreciation for life since being diagnosed with the disease. Men within this study shared their stories in their own language and in their own words. While many spoke of similar fears and concerns, parallel options and barriers; each man offered a unique and distinctive account of his own personal illness trajectory. The accounts presented in the following two results chapters reflect a continuum of personal journeys; both positive and negative. While each man described a very personal account of his illness experience; all participants acknowledged that in one way, or another, prostate cancer had transformed their lives.

The findings presented in chapters 4 and 5 of this thesis are specific to the men within this study and should not instinctively be assumed as generalizable to any other population. In spite of this caution, however, the knowledge presented within the context of this study may offer insight into the sociocultural contexts of other population groups facing similar chronic illness situations. In this first results chapter, findings are presented in reference to men's overall

experiences with prostate cancer along their personal continuum of care; from the circumstances surrounding their initial diagnosis to their selection and receipt of treatment for the disease. The role of the spouse (or partner) and the role of the primary care family physician were also documented as being important during various phases of the illness occurrence. In addition, particular attention was given to the unique geographical and linguistic contexts influencing participants' experiences navigating the health care system. For example, participants from this study travelled, on average, to two different communities during three unique visits prior to obtaining their diagnosis of prostate cancer. In addition, accessing treatment for their disease required most of these men to travel outside of their home communities, for extended periods of time and for many, was received by professionals who did not speak their preferred language. In order to capture the essence of these men's experiences while being culturally sensitive to the populations of interest, the presentation of relevant quotations in the following chapters will occur in the language of the respondent's interview. Within the analytical and interpretive phase of this project, honouring each respondent's use of language is recognized as an important component in both the maintenance of the scientific rigour of this research project (Regmi et al., 2010) and in the acknowledgement of the contextualized reality in which language, culture and experience coexist within the occurrence of illness. In sum, this first results chapter provides a narrative of men's experiences from the time when they were first diagnosed with prostate cancer to the process of selecting and receiving treatment for their disease.

4.1 Bearing the Diagnosis of Prostate Cancer

Northeastern Ontario Francophone men who were diagnosed with prostate cancer faced a mirage of feelings and emotions. As described above, their reactions to hearing the news were as varied as the men themselves. The response of both the men and their spouses' were influenced by several factors including, but not limited to, the manner in which they were told of their disease, the presence or absence of symptoms at their time of diagnosis, their past or current experience (theirs or a close relative's) with serious illness and their familiarity (or lack thereof) with the health care delivery model. The language used during their medical interactions also played a key role in participants' ability to understand both the condition and context surrounding their diagnosis of prostate cancer.

When questioned on their reaction to the diagnosis of prostate cancer, many men expressed feelings of fear and shock, while others described remaining calm and collected. For some, being told they had prostate cancer was seen as a death sentence, while others described feeling validated with the diagnosis since the symptoms they were experiencing finally had a known cause. Participant reactions were predicated by things such as the vehicle and method of delivery of the news. For example, one participant spoke of his distaste for the manner in which his locum specialist delivered the news of his diagnosis of prostate cancer. Feeling as though the specialist was too busy to care, Éliam shared, “*T’sais quand t’arrive avec un médecin-là qui semble avoir aucune sympathie ou quoi, c’est ça, ça, ça. Vas t’en*”. Clinicians often fail to adequately meet prostate cancer patients' information needs; and different patients may receive dissimilar kinds of information from different attending specialists (Cohen Castel et al., 2011) which can lead to a communication gap between the provider and the patient. This communication break may be further exacerbated within northern and rural communities where, due to the shortage of in-house specialists, many communities are serviced by visiting or locuming specialists. In other words, the reality of the current health care service delivery model in northern communities often translates itself into a patient, like Éliam, having to travel to see one locum specialist to receive his screening tests (e.g., biopsy) and yet another locum specialist to receive the test results and a diagnosis. This can cause the patient to have increased feelings of anxiety, uncertainty and disbelief over his cancer diagnosis. While family physicians can often mitigate some of this uncertainty by helping to bridge the gap within northern patients' continuity of care (Katz & Katz, 2008), the opposite can also be seen to be true. For example, when one study participant, Isodore, asked his family physician questions about the specialist (e.g. Was he a good specialist? Did patients like him?) he was being referred to, he recalled his doctor being very dismissive and answering, “*Ah, je le connais pas.*” When probed on how his family doctor's response made him feel, Isodore described his unease with going to see a specialist that couldn't be “vouched for” and identified the fact that his family doctor would send him to a specialist he knew nothing about as a sign of a lack of professionalism. He stated:

J'aurais aimé que mon médecin de famille, aurait pu m'encourager d'aller voir un tel spécialiste... pas me dire ” Je le connais pas, je sais même pas comme qu'il est! ” Ça j'ai pas trouvé ça bin bin professionnel là... Tu pourrais au moins faire un effort pour s'assurer que où qu'il t'envoie... Si t'as des questions...j'avais pas

confiance bin bin à... à ça là. C'était, c'était un Égyptien. Il m'a donné sa carte pis c'était même pas marqué (MD) dessus, c'était, c'était drôle t'sais... parce que tu sais les initials là? (...) Je lui avais demandé si c'était un vrai docteur à cause qu'il venait de l'Égypte... pis en tout cas... j'aurais pas dû dire ça, mais quand tes ses nerfs, quand tu te fais diagnostiqué pis euh... tu veux pas te faire opérer, tu peux pas... tu te trouves toutes sortes d'excuses eih!

Isodore's candour was reflective of many of the frustrations participants shared throughout the course of this study. Within these smaller northern communities, knowing your provider, either personally or by proxy of another person in a position of trust, was often viewed akin to being offered high quality care. Reputation and recommendation went hand in hand within men's perceptions of professionalism from their service providers in relation to their diagnostic experience. In addition, receiving a recommendation for a particular specialist, or the lack of said recommendation such as was the case with Isodore above, was viewed as importantly as all the other information provided during this initial phase of diagnosis. In fact, the amount of information men were given at the time of their diagnosis was shown to greatly influence their initial reaction to having prostate cancer. A recent study by Denis, Joniau, Bossi, Baskin-Bey and Fitzpatrick (2012) showed that most specialists spent between 15-29 minutes on delivering the diagnosis of prostate cancer to patients and roughly the same amount of time on explaining treatment options. This study also demonstrated that 35% of specialists and 48% of patients considered this amount of time insufficient (Denis, Joniau, Bossi, Baskin-Bey, & Fitzpatrick, 2012).

The psychological adaptation to a cancer diagnosis is often characterized by significant distress (Perczek, Burke, Carver, Krongrad, & Terris, 2002). Most Francophone men in this study admitted to experiencing some element of shock upon receiving the news that they had prostate cancer. When asked about his reaction to the diagnosis of cancer, Déjean Jr. described it as “*une bombe*” while for others like Pascal, hearing the words “you have prostate cancer” equalled a death sentence. While feeling “attacked” by a cancer diagnosis has often been cited within the literature as a default sentiment, this is often caused by the social misconception that all cancer is terminal (Mukherjee, 2010). Such was the case for Pascal who shared:

Bin le cancer, aille le cancer! Quelqu'un qui parlait d'un cancer... Aille c'était pas drôle là! On va mourir. C'est pas absolument une belle affaire à entendre dire que t'es pris du cancer... Aille, on va mourir. J'suis trop jeune, j'ai ainqe 75 ans!

Pascal's declaration that at age 75, he was too young to die from prostate cancer speaks to the changes occurring within our contemporary understanding of the concepts of aging and of quality of life in older adults. In fact, within Canada's aging population, we continue to witness an increased academic interest in the study of older adults' general health-related quality of life (Lusina, Langton, Sims-Gould, & Khan, 2010; Raina et al., 2009; Ramage-Morin, Shields, & Martel, 2010; Weir, Meisner, & Baker, 2010). Like Pascal, Isodore, aged 73, spoke of the fear he felt upon receipt of his diagnosis, "*Bin dans... tu sais pas comment que c'est... tu t'imagines toutes sortes de choses quand tu te fais diagnostiquer. T'as pu confiance à grand, à grands-choses là.*" Thus, the fear and disbelief from a diagnosis of prostate cancer transcends beyond a man's age; regardless of its advancement. Being afraid, as stated by Isodore, leads many men to fear the unknown and to lack trust in a system that they know so little about.

For many participants within this study, the feelings of shock and fear they described upon hearing the news that they had prostate cancer were linked to their current understanding of the disease, or lack thereof, at the time of their diagnosis. Almost half of the participants in this study admitted to knowing little or nothing about prostate cancer when they received their diagnosis and confided that obtaining that information was often challenging for them. A recent study by Ernstmann, Jaeger, Kowalski, Pfaff, and Weissbach (2013) demonstrated that age was a contributing factor in the amount of information older men received about prostate cancer during their diagnostic appointments. According to their prospective observational study of 2,482 newly diagnosed localized prostate cancer patients, Ernstmann and colleagues (2013) found that patients aged over 75 years old received less information on treatment options than their younger counterparts and concluded that specialists could improve their dissemination of information in areas such as rehabilitation, second medical opinions and self-help groups (Ernstmann, Jaeger, Kowalski, Pfaff, & Weissbach, 2013).

However, other researchers have found that some older men appear to maintain a sense of ambivalence in regards to obtaining more precise information about their prostate cancer condition and the potential effects of various treatments on their quality of life (Wedding, Pientka, & Hoffken, 2007). Such was the case with Stéphane, who described a feeling of being “attacked” when he heard of his diagnosis, yet admitted that he never posed any questions regarding his treatment options or sought any clarification on the information he was given by his urologist during his diagnostic visit:

Supposément que la face m’a changé (rire). Mais, j’ai resté surpris, mais ça se fait tellement vite que... on change, mais je... je sais pas. On comprend pas vraiment là, on est dans le, on est quasiment... Comment je dirais ça? On voit plus... Ça nous assomme.

Stéphane’s account of the shock he felt during his first meeting with his urologist was exacerbated by the quickness of the meeting. Feeling overwhelmed and pressured for time, he did not feel as though he had the time to fully process the information he was given in a manner that would allow him to feel comfortable asking any questions.

The reasons why men may choose to be silent during diagnostic meetings are varied (Durant, McCray, & Safran, 2012; Friedman, Thomas, Owens, & Hebert, 2012; Kannan & Veazie, 2014; Mroz, Oliffe, & Davison, 2013). Bungay and Cappello (2009) conducted in-depth interviews with more elderly prostate cancer patients in order to try to grasp why those who did not fully understand the potential consequences of various treatment options did not seek additional information or clarification during their diagnostic consultations. Their results pointed to an apparent ambivalence among older prostate cancer patients about finding out more information about their condition partly because of their beliefs about the normal aging process and partly because of the trust they had in health providers and their overall satisfaction with the care that they had received up to that point (Bungay & Cappello, 2009). This dynamic of trusting the medical professionals to the point of ambivalence towards obtaining more comprehensive information regarding a diagnosis of cancer and the available treatment options is not uncommon (Feldman-Stewart et al., 2011; Sartor, 2008; Song et al., 2013). In fact, for some men, trusting anyone whether it was a spouse or close friend if not the specialist allowed them the liberty to shut down upon hearing their diagnosis of prostate cancer. Such was the case for Doménic, who

shared his inability to register the information his physician was giving him when he received his diagnosis, “*Puis écoute, tu te fais dire que t’a le cancer, pis y te donnent des options là ... t’a peut-être des options à prendre, mais t’a le “ C ” word dans tête là encore.*” When asked how he handled this situation or if he sought clarification from his specialist at a later time, he explained that his wife, who was present at the appointment, was the one who took detailed notes and posed questions in order to help him understand the information they were being told:

Ben comme de raison c’est un choc. Pis c’est pour ça que, comme à toute les fois que j’allais j’étais avec mon épouse parce que à savais qu’y se disent des choses que tu captes pas tout l’temps parce que tu t’fais dire ça là, les autres affaires on dirait ça passent. Ça s’en allait à côté de toi, t’a juste une chose là tu t’fais dire que t’a le cancer. Pis là, ben c’est là que elle avait compris toutes les choses pis après ça on discutait de d’ça.

The presence of a supportive other during the diagnostic meeting has often been cited within the literature as a positive influence on men’s diagnostic experiences (Brothwell, & Symons, 2007; Couper et al., 2006; Docherty, Sanders, Pedro, Bantum, & Galbraith, 2006; Friedman, Thomas, Owens, & Hebert, 2012; Sjoval et al., 2010). One participant, René, shared an account that echoed the literature when he described how upon hearing the words “you have cancer” he was in shock and was unable to process any of the information he was being told. Like Doménic above, René shared that it was also his wife who was able to take charge, keep calm and absorb the information they were being given by their specialist. He explained:

Ah bin, là moué j’ai... (Rire) (Se met à pleurer) Je m’en rappel pas de tout. Quand qu’il m’a dit là... “ T’as le cancer ” j’ai quasiment fait un blackout. Je savais pu, j’ai dit “ Ça ce peut pas ” là c’est ma femme qui a pris la relève. C’est elle que... qui a pris les informations, il a bin des affaires... je m’en rappelais pu d’avoir entendu ça pantoute.

Shock and frustration were common themes expressed by participants upon facing a diagnosis of prostate cancer. More so, many acknowledged a general lack of prior knowledge about the disease. The very fear of death inspired by simply hearing the words “you have cancer” is an additional level of shock and suffering that many patients experience (Mukherjee, 2010).

For others, the shock they experienced hearing the news that they had prostate cancer was intensified by the fact that they were symptom-free and thus believed to be healthy, at the time of their diagnosis. For example, Hébert, a self-identified healthy and compliant patient, described feeling stunned by the news that he had prostate cancer because he had undergone regular annual check-ups with his family doctor and was completely symptom free at the time of his diagnosis. In fact, upon receipt of the news of his cancer, Hébert was so angered that he insisted on a second opinion. When asked to describe the moment he found out that he had prostate cancer, he recalled:

Pis là ça m'a choqué. J'ai dit non, m'a va voir un autre euh, euh (...) un autre médecin pour vérifier vraiment si euh, parce que ça, ça m'avait choqué un peu. Mais c'est normal, quand tu t'fais dire en plein visage que t'a l'cancer euh, tu prends pas t'suite. Ça fais que j'ai retourné voir l'docteur, j'ai dit j'veux voir un autre, faire un autre check-up d'un autre docteur. C'est mes droits.

Hébert's skepticism regarding his diagnosis was founded in his denial that this was really happening to him. When further probed about his reaction, he described how the manner in which he was told added to his angered reaction:

La manière qu'y m'a dit ça y dit ben, j'étais comme toi là en face de toi, y dit, y dit, y dit votre test dit que vous a ... c'est cancéreux. Pis y dit, pis y m'avait dit, y dit c'est pas grave, y dit on va t'opérer c'est pas grave. Ça sera pas long pis comment toute les conséquences vous allez avoir pis toute. Y dit, non non ça sa m'a choqué. T'sais, j'm'attendais pas. Mais, t'sais, tu, quand tu t'le fais dire toi-même. Un voisin c'est pas grave, mais toi-même t'est atteint d'un cancer, tu, tu réagis pas d'la même manière. Non, quand c'est, ça, ça te frappe c'est pas pareil. C'est pas pareil.

Iréné Jr. also expressed a lot of anger towards his doctor when he described his prostate cancer experience. Having suffered various symptoms (e.g. incontinence, increased pain during ejaculation), he described feeling as though his family doctor was dismissive of him and his multiple requests for diagnostic tests; advising him that they were caused by previous health issues. After years of increased pain, Iréné Jr. finally insisted on being referred to a specialist.

Within one month of his referral, he received his diagnosis of prostate cancer. In his opinion, he had finally been given the cause of the pain he had endured over the past 10 years. He shared:

J'ai pâti pour dix ans là... pis ils disent que les médecins euh... pas les méde... ouin, que les médecins disent que... sur la télé partout, si t'as des symptômes... ou selon... d'aller voir votre médecin. Bin les médecins sont pas là, ou... ils sont pas dévoués... ou ils te croient pas quand que tu dis que chose... (...) pis j'ai duré de même pour dix ans de temps.

For over ten years Iréné Jr. had been suffering from symptoms that he would later attribute to his prostate cancer. His apparent anger and frustration with his family doctor stemmed more from the fact that he felt as though his physician ignored his requests for referrals. Feeling unheard and being refused a referral to a specialist, led Iréné Jr. to experience what he termed the “worst years of [his] life.” As such, hearing his diagnosis of prostate cancer was a relief for him since he finally understood the root cause of his pain.

Many of this study's participants expressed a general lack of understanding about prostate cancer and its risk factors, symptoms or consequences prior to their own diagnosis. For example, Isodore explained his difficulty accepting the news of his diagnosis since he assumed that living a healthy lifestyle protected him from such diseases:

Je prenais pas d'alcool, pis je fumais pas pis euh... je faisais beaucoup de... je faisais très attention aux aliments pis je me tenais en forme. Ça fait que... j'ai trouvé que, j'aurais aimé être capable de pas avoir de cancer parce que je pensais jamais d'avoir le cancer. J'ai tout le temps fait attention pis euh... tout d'un coup il te déclare que t'as le cancer.

Furthermore, his intense belief that all cancers were terminal, coupled with his lack of concrete information on various treatment options and potential outcomes based on his particular case, led him to fear the worst:

Bin, je ne connaissais pas grand-chose à propos du cancer de la prostate, euh... j'avais une idée que le cancer c'était terminal... Il a des personnes comme Mr. X. qui est décédé. J'avais un ami Mr. Y. qui avait un autre cancer, t'sais quand t'avais le cancer, ça faisait pas bin bin, tu pouvais pas vivre avec ça là... Je ne

savais pas que le cancer de la prostate tu pouvais te le faire enlevé pis que t'avais plus de cancer. Je ne savais pas ça. Je pensais mouer que c'était comme, le cancer de l'estomac, ou l'œsophage ou quelque chose comme ça. (...) Je pensais qu'un cancer c'est un cancer... C'est pour ça que j'étais... t'sais... il m'a pas expliqué là que j'étais pour être correcte.

Another participant, Zachérie, described that while his family history of prostate cancer rendered him a little more informed about the disease, it was his younger brother's recent diagnosis that drove him into action:

Actually... how it came about was that... my kid brother was... went for a medical, a full medical after he quit smoking... and they checked his prostate and they found bumps or whatever (...) So that's when I got a bit of a scare, because he was three years younger than me. So... and I went and got checked by my doctor (...) and one of the samples they took was cancerous, so... And I found out by my family doctor. He called me in and... he left a message at my place saying, "If you a chance, come in and see me" and I'm thinking he's been my family doctor for 25... Maybe, almost 27 years, and has never left a message on my... (Laugh) my answering machine... so I figure, well... yeah I'm thinking, jigs up...

Although Zachérie's family history of prostate cancer may have helped inform him about the disease, his reaction to his own diagnosis mirrored the sense of shock expressed by many participants:

It was like... a sledge hammer in my noggin. (Laughs) Yeah, because I was standing, and when he [Family Physician] told me, when, he just said... (...) "It's cancer." So... but then I... I just sat down for a bit there, and I'm thinking... Oh my God! And the thing is, is that... you uh... well maybe not everybody's the same... but I... I guess I tend to go to the extreme, right? I'm thinking "OK, shit, I don't have much time" because I'm thinking... but like because I see, like you know... people that are diagnosed with cancer...and cancer is... you know, you have to make sure that your paperwork is in order and uh... like you know, maybe... get the sandwiches ready and stuff (Laughs).

Receiving a diagnosis of, and treatment for, prostate cancer can be a major life stressor (Van den Bergh et al., 2009; Van den Bergh et al., 2010;). However, there has been quite a level of variability reported among prostate cancer patients. A prospective longitudinal study conducted by Steginga and collaborators (2004) to assess psychological and decision-related distress after the diagnosis of localized prostate cancer revealed that prior to treatment, 65% of the men reported high or moderate levels of intrusive thoughts about the cancer. At the two-month follow-up, reported scores had reduced to 48% for avoidance and 32% for intrusion. However, results from an earlier study conducted by Bisson and colleagues (2002) suggested that men with early localized prostate cancer have low levels of psychopathology overall, reporting that only 14% of participants indicated having intrusive thoughts and feelings of avoidance in the two-week period following their diagnosis of prostate cancer (Bisson et al., 2002).

It is clear from the above studies that a diagnosis of prostate cancer is experienced in a variety of ways; including men's emotional well-being. While some men may appear unaffected by the cancer diagnosis, others may utilize a variety of emotional mechanisms in order to help them process the information. Within my research population, denial and avoidance were common themes expressed by participants when discussing their initial diagnosis of prostate cancer. For some, it was the embarrassing symptoms associated with prostate cancer that contributed to their reported reluctance to seek help. For others, it was the complete denial of symptoms altogether. Many men described illness and help-seeking as direct threats to their masculine identities. For example, Onézime conceded that after one appointment with his family doctor about his problems with urination, he never returned for a follow-up. He shared:

J'avais de la misère à faire pipi. Je m'suis apporté chez le docteur. Il m'avait dit " Tu reviendras dans deux semaines " mais moué je viens de... de... (Rire) une sorte de monde où on va pas voir le docteur à moins d'être bin malade. Parce que c'est du monde dangereux les docteurs. (Rire) T'sais, ça fait que j'ai pas retourné.

Onézime's reluctance to return to see his family physician may have represented more of an avoidance tactic rather than a veritable belief that "doctors are dangerous people" and as such, should be avoided. In fact, current literature supports the notion that this type of rationalization promotes either a delay in usage or complete avoidance in seeking medical assistance for

symptoms that call into question various traditional scripts of masculinity (e.g., being unemotional, being self-reliant, being powerful, being independent, defining one's worth in terms of sexual potency) (Helgeson & Lepore, 1997; Helgeson & Lepore, 2004). For some men, like Onézime, it was easy to rationalize the subtle symptoms of prostate cancer as those of normal aging (Baker et al., 2012; Krumwiede & Krumwiede, 2012). In fact, this rationalization led to a level of personal negligence in the face of a disease where initial time at diagnosis is of the greatest importance. He defended:

C'est que les symptômes sont pas si forts que... le cancer du poumon, bin quand que les symptômes paraissent, il est trop tard généralement là, mais t'sais, les symptômes sont pas tellement visibles. Un peu de difficulté à uriner, mais j'ai dit "Je vieillis, c'est normal" (Rire)... Puis ma génération, t'sais (Rire). Je faisais une farce avec ça, les docteurs... il faut pas aller les voir à moins d'être bin malade', parce qu'ils peuvent te diagnostiquer des maladies que t'as pas pis tu peux en mourir (Rire)... Oui, oui, oui! Bin oui, on va pas voir le docteur à moins d'être bin malades (Rire). ...Bin oui ça l'attarde, bien sûr que ça l'attarde les choses. Bin oui ça l'attarde les choses... Pis on vient qu'on se fatigue. (Pause) ...Et puis quand j'ai été diagnostiqué bin mon médecin de famille aujourd'hui là il m'a dit " Ça fait tout de bin 5 ans que tu traines ça ".

Onézime's account also alluded to a sense of mistrust towards medical professionals. In stating that "you should not go see them unless you are really sick," he demonstrated a social and cultural tendency to view seeking medical help as a risky behaviour. While, as pointed out by Luhmann (2000), trust is not directly prescribed by cultural imperatives or social structures; the presence or absence of trust is only possible in a situation where the possible damage may be greater than the advantage one seeks (Deutsch, 1958). For Onézime, the potential consequences of seeking medical assistance and finding out what was actually causing his urination issues represented more of a risk than the immediate consequences of the symptoms he was experiencing which he could rationalize as a normal part of aging.

However, for another participant, Stéphane, the risk of not knowing was understood as one of greater concern than dealing with any potential outcome. In fact, it was his inherent sense that something was "off" with his body, beyond the ordinary health issues of being a 63 year old

man, which led him to insist on further diagnostic testing. In the face of an asymptomatic disease, he explained:

J'avais aucun signe de... que je pouvais avoir ça, à part que sur le côté sexuel, ça l'allait bien, j'ai jamais eu de problèmes là, le seul... je me sentais toujours fatigué. Puis j'allais voir mon docteur puis il disait " Bin, OK, ouin bin... l'âge ". J'ai commencé à travailler jeune puis, dans le bois, pis je travaillais fort. À onze ans je travaillais. Il dit "Peut-être que t'as travaillé fort quand t'étais jeune, pis tu vieillis " t'sais comme... puis euh, il faut réaliser ça. Mais je disais " Si c'est ça vieillir, ça l'a pas de bon sens ", parce que c'était une autre sorte de fatigue que je sentais, mais je savais pas c'est quoi que ça pouvait être. Il avait quelque chose qui clochait. Comme c'est, à partir de ce moment-là que j'ai commencé à écouter mon corps. T'sais des fois, même si on n'est pas malade on... tout va bien, mais des fois on devrait écouter un peu, quand on est fatigué arrêter ou... écouter notre corps un peu plus. Puis que, c'est comme ça que ça s'est découvert.

Stéphane's account demonstrated an initial approach to health care management that was proactive and responsive to what he was feeling within his own body. However, he later admitted during the interview that his diagnosis of prostate cancer may have been somewhat delayed since he was too embarrassed to discuss the sexual symptoms he had been experiencing with his family physician in the years preceding his diagnosis. When pressed why he was embarrassed to discuss these issues with his family doctor, he responded in reference to men's awkwardness and prudishness relative to their own sexual health and well-being:

Ça les gêne. Beaucoup de monde, ils n'en parlent pas. Beaucoup, beaucoup ils ont pas besoin... entre hommes là, je pourrais, je suis certain certains s'il avait 10 hommes icitte, aïne un parlerait. C'est surprenant, c'est pour ça que je suis ouvert avec toi, parce que, j'ai espérance que ça peut aider quelqu'un d'autre.

Avoidance tactics based on socially prescribed beliefs of masculinity were shared among participants in this study. For example, Doménic confided that while he was meeting with his family physician on a regular basis, he was unable to admit to some of the symptoms he was experiencing. He shared, "Comme homme, tu sais, je .. oh, everything's okay, but it wasn't. Okay. I was in denial." When probed, he admitted that it was his fear of the digital rectal exam

(DRE) that led him to denying the presence of any symptoms. He stated, “*J’voulais pas m’faire checker parce j’sais.... T’sais...they’re playing with your manhood. That’s what it is. Bottom line, that’s what it is. It’s your manhood.*”

Medical practitioners routinely use digital rectal exams to screen for prostate cancer. This manual examination is performed by a doctor putting a gloved finger into the rectum of the patient in order to physically examine the prostate and determine whether or not it is larger than it should be or if there are any unusual growths on the prostate or in the rectal cavity. The invasive nature of this procedure is often cited as a threat to men’s masculinity (Forrester-Anderson, 2005; Paiva, Motta, & Griep, 2011; Wall & Kristjanson, 2005; Winterich et al., 2009) thus causing many of them, like Doménic, to avoid seeking help for sensitive symptoms they may be experiencing. A recent study conducted by Winterich and colleagues (2009) examined how men’s constructions of masculinity affected their attitudes toward prostate cancer screening and found that men in their study tended to evaluate digital rectal exams even more negatively than colonoscopies because they viewed “penetration with a finger” as a direct association with performing a “gay sexual act”. Gomes and colleagues (2008) also found that the nature of the digital rectal exam violated men’s “interdicted space” by fostering a situation of embarrassment, fear and/or shame for the patient (Gomes, do Nascimento, Rebello, & de Araujo, 2008).

Recognizing a diagnosis of prostate cancer as a subjective experience, the manner in which men perceive and interpret their diagnosis often extends beyond the individual. For example, upon hearing that he had cancer, Félix shared that he was more concerned about how others would react. He shared, “*C’est justement... (Pause) Ils ont dans leurs têtes que les autres vont les considérés différemment... s’ils ont un cancer. Surtout l’cancer d’la prostate, à cause des effets secondaires.*” Highlighting the negative stigma associated with prostate cancer, especially the sexual side effects of treatment, Félix’s account referenced his fear of how others may view him differently now because he has a disease that causes side effects that contradict dominant social norms prioritizing “real” men as potent, powerful and active (Wenger, 2014).

As it has previously been noted, all treatment modalities for prostate cancer can have a negative effect on both sexuality and male fertility. As stated by Colson (2012), minimizing adverse sexual side effects and maintaining a healthy sexual life are some of the largest concerns

of a majority of men when facing a diagnosis of prostate cancer and its treatment options. These authors advocate the importance of assessing men's and more specifically, the couple's (as applicable) sexuality prior to their diagnosis of prostate cancer in order to deliver complete information and to consider early and appropriate treatment options at the request of the couple (Colson et al., 2012).

Klaeson, Sandell and Bertero (2012) also advocated that cancer care should be organized so as to enable all aspects of sexuality to be acknowledged and discussed. From their "lifeworld perspective" study of how men diagnosed with prostate cancer experienced their sexuality, they identified their participants' views of the sexual consequences of treatment for prostate cancer as "having (their) elixir of life stolen" (Klaeson, Sandell, & Bertero, 2012, p. 1184). In fact, this study highlighted the deep struggle men had when dealing with the sexual side effects of the various treatments for the disease and its effect on their ability to have and experience intimacy. This sense of mourning can not only cause prostate cancer patients to renegotiate their own sexuality, but as pointed out earlier by Félix, it can also cause anxiety and delayed entry into the health care system by men fearing the impact of a diagnosis on their social standing within a dominant masculine environment.

While the information provided, thus far, offers very little differentiation in the experiences described by Francophone respondents and those of the general population diagnosed with prostate cancer, the following sections will offer insight into some of unique circumstances experienced by the Francophone participants in this study by virtue of environment and lifestyle factors associated with their living within a linguistic minority situation in a northern geographic context.

4.1.2 Family Physicians' Support & Influence

As previously identified, prostate cancer therapy outcomes are highly heterogeneous and are often contextualized in reference to the individual, social and cultural contexts in which diagnosed men belong (Baade, Aitken, Ferguson, Gardiner, & Chambers, 2010; Chambers, Ferguson, Gardiner, Aitken, & Occhipinti, 2012; Halbert et al., 2010). Within this study, Francophone men from Northeastern Ontario shared their experiences at the time of their diagnosis of prostate cancer which identified some of the intricacies surrounding the health care

delivery model within this catchment area. For example, René, who was 62 years old at the time of his initial diagnosis, offered an interesting account that highlighted some of the unique circumstances that can occur within smaller, more rural communities where access to health services is limited to the resources available. In René's particular case, the local physician, and only practicing family doctor at the time in his community, also happened to be his high school friend, whom he saw socially at community dinners, local events and other social outings. This familiarity, René admitted, may have complicated the physician-patient dynamic and in his opinion, may have delayed his initial time at diagnosis. He recounted:

Moi ça fait longtemps que mon docteur moué... j'allais voir mon docteur, c'était un de mes chums de collègue, on avait été au collège ensemble. Pis t'sais... quand on passait, on passait notre médical là, il faisait exactement ce qu'on voulait, si on voulait pas passer tel test rectal, il nous le passait pas. Il disait " Bin... c'est toué qui le sait".

Upon receipt of the news of a close family member passing away from prostate cancer, René insisted that his physician-friend complete a digital rectal exam on him, regardless of the uncomfortable nature of the procedure:

J'ai dit " On va... il faudrait passer... il faudrait que tu me passes le test rectal le plus taux possible". Il dit " Je sais que t'aimes pas ça" " Je sais que j'aime pas ça certain. Ceux qui aiment ça ont des... ils ont peut-être un... (Rire)... ceux qui aiment ça sont pas normal! " (Rire) Ça fait que... là j'ai dit à X, j'ai dit " Bin... tu vas me passer ça le plus vite possible" " Bin... " il dit, là on était dans le mois de juin, au commencement de juillet, il dit " Ton test médical annuel il est dû au mois de décembre. M'a te le passer au mois de décembre" Ça fait que là je pensais à ça, j'ai dit " Non" j'ai dit " Tu vas me passer ça plus vite que ça" Il dit " Qu'est-ce que tu veux? " j'ai dit " Passes moué-les tout de suite". Il dit " T'es tu prêt? " j'ai dit " Bin, sure j'suis prêt. (Rire) J'ai pas eu le temps d'y penser, j'suis prêt certain". Bin il dit " Monte sa table". Il me monte sa table, pis là d'habitude ça prend dix secondes eh? Eille là ça prenait du temps! Ouf! Pis là je me... pis là finalement, il arrive, il dit, après que j'ai débarqué de sa table il dit " Là... " il dit " ... je t'ai trouvé une bosse". Ah bin maudit!

René's testimony pointed to the anxiety or embarrassment that some men feel about receiving screening for prostate cancer; particularly for the digital rectal exam portion of the screening test as compared to the prostate-specific antigen blood test. Within smaller communities where the relationships between the physician and the patient can transcend various social spheres, the uncomfortable nature of the physical examination can be even more problematic since patients are often in positions where they must interact with their family doctors within social and cultural settings. René's friendship with his family physician made him more vulnerable during an already uncomfortable situation admitting that he never pushed for a full physical because he didn't want his friend doing it. Upon hearing of the death of his family member, René felt as though he was forced to overcome this unease. René's wife also acted as a catalyst for action with her insistence that he stop "acting like a baby": *"Puis elle dit.. C'est elle là... elle dit vas-y. Toute de suite. Appelle-le. Maintenant. Arrêtes-moi ça cette affaire de bébé là... et va y le faire faire!"* The apprehension and awkwardness René felt in relation to the invasive nature of the physical DRE test, combined with a general lack of knowledge and a hesitancy to discuss any sexually-related health problems with a medical professional have often been cited as significant barriers to prostate cancer screening within the general population (Forrester-Anderson, 2005; Hinchliff & Gott, 2011; Wenger, 2014; Klaeson, 2013).

While René's personal relationship with his physician and the social implications of these dual role relationships potentially led to his delayed diagnosis, in other participant cases within this study, it was a genuine lack of access to a primary care family physician that facilitated men's denial of their symptoms and ultimately delayed their time at diagnosis for prostate cancer. For example, when asked about his pre-diagnostic experience, Cédric Jr. shared, *"Moué ça va mal, j'me pisse sur le bout des pieds mais j'avais pas d'doctor so quoi faire? Facile de te dire y a rien à faire quand t'en a pas de docteur! Et aller attendre à clinique pour ça – puff!"* When questioned on whether he thought not having a family physician affected his time of diagnosis, he replied, *"Ouff... oui et non. Oui, parce que y avait personne pour me dire que c'est pas normale. Non, parce que je ne sais pas si j'aurais été même le voir! But ma femme m'aurait poussé à y voir...ca c'est sûre!"* Cédric Jr.'s account clearly points to the significant role his wife played in his disease diagnosis. In fact, many studies (Au, Zauszniewski, & King, 2012; Boehmer & Clark, 2001b; Lafaye, Cousson-Gélie, Petit, & Bouisson, 2007; Tannenbaum

& Frank, 2011; Wallner et al., 2008) confirm that spouses are often responsible for health maintenance and illness care for their husbands; especially in later life (Bassett, Bourbonnais, & McDowell, 2007; Ernstmann et al., 2013; Schone & Weinick, 1998). In addition, findings from a recent study by Docherty, Brothwell, and Symons (2007) showed that inadequacies in patient and spouse knowledge and awareness of prostate cancer (prior to and at the time of diagnosis) contributed to delayed contact with health care professionals, increased levels of shock at diagnosis, preferences regarding decision-making, health judgments, including the use of the prostate specific antigen test (Docherty et al., 2007).

While it is clear that the provision of accurate and relevant information and support throughout the medical process is pivotal in men's experiences with prostate cancer, the unique nature of health service delivery within northern and rural communities can generate distinctive challenges and circumstances for both the patient and the health care provider. Sadly, many northern and rural communities lack access to family doctors; particularly French-speaking physicians (Timony, Gauthier, Hogenbirk, & Wenghofer, 2013). And while many, like Cédric Jr., may delay entry into the system for personal issues related to their own fear and anxiety, the lack of access to a primary care provider cannot be overlooked. Another participant, Éliam, also shared of the anxiety he felt while waiting for the results of his biopsies. In the following account, he discussed how after waiting six weeks for his results, the fear of not knowing pushed him to contact his specialist's office directly. Éliam then explained that his specialist returned his call at nine o'clock at night and told him over the telephone that he had prostate cancer. When questioned on receiving the news over the phone (which in itself is uncommon in practice), he simply replied that, "*ça se fait souvent ici, pourquoi pas?*" However, Éliam later admitted that the length of time it took for him to receive the results of his biopsy allowed him to live in denial, while simultaneously fuelling his sense of anxiety. He recalled that during his initial biopsy, the specialist indicated he would call him very soon with results yet after six weeks, he could no longer continue to live with the "not knowing." He explained:

J'étais supposé recevoir les résultats t'suite mais je les ai pas eu, ça faisait... six semaines, ça fait que là j'ai décidé d'appeler le docteur... il dit jamais les résultats de ça, ça fait que... j'ai appelé le [spécialiste] qui m'avait passer la

biopsie pis il a rappelé t'suite le soir pour dire que (Soupir)... c'était le cancer mon... mon... ma prostate.

A diagnosis of prostate cancer can often produce anxiety, psychological distress and denial in the men who receive it (Kronenwetter et al., 2005; Kunkel, Bakker, Myers, & Oyesanmi, 2000). Such was the case for Éliam, who shared that upon hearing the words “you have prostate cancer,” found himself retreating in what he termed a “four day self-imposed isolation”:

(Soupir) Ah ça... (Pause) quand qu'on attend parlé de cancer... (Voix très basse) ça frappe toujours. (Pause) (En pleurant) Le docteur m'a appelé à neuf heures du soir pis il m'a dit ça... euh... (Pause) j'ai fait comme tout le monde, pis leur réaction. Euh, le lendemain je suis allé travailler (Pause)... pis là les gars s'apercevaient que j'avais quek chose, mais j'ai pas été capable de parler. (Il a beaucoup de difficulté à dire ce qu'il veut dire) (En pleurant) J'ai été euh... quatre jours, jusqu'à tant que, je me suis renfermé. C'est ça qui est arrivé les quatre premières journées, je trouvais ça terriblement dur. Là j'me suis renfermé pis j'voulais pas en parler. (Pause) Ça pas été facile jusqu'à tant que je réalise que c'était pas bon à faire de se renfermer d'même. Au bout des quatre jours bin là je l'ai dis, j'ai dit... je suis pris du cancer. Asteure que... j'ai pas peur d'en parler que... même mon problème que j'ai là, j'ai... t'sais je le cache pas (Pause) C'est comme je dis au monde mouer tout, euh... essaye pas de se cacher avec ça t'sais... même d'un coup, quand que la question m'est posée t'sais... ça me rappelle des souvenirs, c'est pour ça que c'est pas... c'est pas facile à... passer par là t'sais. J'fais... j'ai fait la même réaction que tout le monde quand qu'ils entendent parler cancer t'sais.

Éliam's reaction was not uncommon as it has been reported that men with prostate cancer will often avoid disclosure of their illness, either as a reflection of their state of denial or in an effort to place importance on maintaining an ordinary life where possible (Arraras et al., 2013; Gray et al., 2002).

4.1.3 Trusting Anglophone Specialists in Northeastern Ontario

Several participants expressed a range of emotions upon receipt of the news of their diagnosis of prostate cancer. Much of this angst was associated with the fear of the unknown and the uncertainty of the future that surrounds a diagnosis of prostate cancer. Such was the case for Éliam, who, as previously mentioned, spent days refusing to admit to himself and to others that he had prostate cancer. However, his experience was also tainted by an uncertainty caused by his inability to understand his English-speaking specialist. He recalled:

Le spécialiste... tu peux pas y parler, tu peux pas d'y pauser une question... euh... pis il parle très vite en anglais. Pis il est pas compréhensible. Il est pas compréhensible, tout le monde ont le même problème, mais c'est le seul spécialiste qui vient ici ça fait que... t'as pas le choix. Ça fait que... c'est pour ça que moi j'y ai dit euh... Bin mouer quand j'y ai dit, j'ai dit " On a pas l'air à se comprendre bin bin", il dit euh... j'ai dit " Je préfère aller voir un autre spécialiste à Ottawa pour une deuxième avis". Ça ça l'a insulté. (Rire) Parce que j'en avais pas confiance parce que j'en avais entendu parler avant, à fait que... Pis ça ça l'avait beaucoup insulté et puis ça fait qu'il dit... Euh là il s'est, c'est là qu'il a dit " Je vais aller chercher une nurse qui parle français, pis je vais te faire répéter en français". (Rire) Il était assez choqué que... il ne voulait plus me revoir après ça.

When probed about the actual communication between himself and his specialist during the telephone call where he received his diagnosis, he shared:

Il m'a pas dit grand-chose il dit " Tes cancéreux", pis il dit euh... j'ai passé proche d'y dire " Pourquoi t'as attendu si longtemps avant de m'appeler pour me dire que c'était le cancer? ". Vu que c'est aïnk' en anglais pis qu'il m'aimait pas (Rire) ...Pis il dit " Je vais te revoir à Timmins", il dit, " M'a, j'va avoir mon schéma pis m'a t'expliqué ça". Il m'a parlé aïnk des affaires de Gleason score là, là...Il parle assez vite pis il est pas compréhensible en anglais, il casse son anglais. C'est un allemand de quek chose pi euh... Bin il disait t'amènera ta femme il dit " On va t'expliquer ça itou". On a rien compris de là, de quessé qu'il nous a dit. Euh... la seule chose qu'on a compris, il dit a femme, il dit " Tu reviendras me voir avec ton mari pis tu m'amènes une bouteille de champagne

dans dix-douze ans d'icitte, il a pas besoin de se faire opérer” (Rire) C’est la seule chose qu’il m’a dit qu’on a compris. C’est pas, c’est pas en français pis... t’sais c’est... c’est pas facile d’aller le voir le monsieur. T’as pas le choix, t’as pas le choix.

Éliam’s account of his diagnostic experience points to a larger issue facing Francophone prostate cancer patients from Northeastern Ontario. While the absence of specialized care practitioners within many of these northern communities in itself represents a departure from an ideal health service delivery model, Éliam’s reflection also pointed to the impact of language on a patient’s diagnostic experience. His inability to both understand and be understood by his specialist left him feeling frustrated and confused. More so, without the ability to communicate and ask questions to the specialist, both Éliam and his wife (who was present during the meeting) had feelings of doubt concerning the medical information they were presented.

Several researchers (Cegala et al., 2008; Davies et al., 2008; Hack et al., 2011; Jayadevappa et al., 2009) have noted that patients are more likely to be satisfied with the physician-patient interaction when physicians provide explicit information and express interest in patient issues other than aspects of the illness, provide an opportunity for patients to talk about their experience, are sensitive to the patient's needs, appear warm and concerned about the patient, answer patient questions and do not dominate the exchange. Yet the possibility of effectively managing these best practices can be threatened by the presence of linguistic barriers. In fact, it has been noted that the most identifiable occasion for conflict is when the patient and health care professional do not share the same language (Bouchard, Chomienne, Benoit, et al. 2012; Chambers, 2000; Chambers, 2008). Such linguistic barriers not only lead to poorer patient satisfaction, they can also contribute to the patient being left with a poorer understanding of their disease and their prognosis, or having difficulty recalling the information they were given about the disease (Bouchard, Chomienne, Benoit, et al. 2012; Chambers, 2008; Hahn, Bode, Du, & Cella, 2006; Trill & Holland, 1993).

Another participant, Pascal, also shared how language played a role in his uncertainty at the time of his diagnosis. He shared that he received his prostate cancer diagnosis from an

Anglophone medical student working with his specialist and although she tried to speak to him in French, he struggled to understand her accent:

C'était une étudiante qui m'a donné les résultats, pis c'était une Anglaise, pis elle essayait de parler en français, pis j'essayais de la faire répéter ça en anglais parce que je comprenais pas tout ce qu'elle disait avec son accent pis tout ça pis les grands mots, pis elle restait là-dessus.

Understanding medical terminology is in itself a difficult endeavour for many cancer patients (Pieterse, Jager, Smets, & Henselmans, 2012). Chapman (2003) examined lay understanding of cancer-related terms oncologists use (e.g. medical jargon, such as technical terms or ambiguous language) when discussing cancer diagnosis and prognosis with their patients and found understanding to be suboptimal and variable (Chapman, Abraham, Jenkins, & Fallowfield, 2003). When this lack of understanding of medical terminology is further compounded by a language barrier, patients often do not correctly understand their diagnosis, prognosis, or treatment options (Bernhard et al., 2012; Bosco, Halpenny, & Berry, 2012; Bouchard, Chomienne, Benoit, et al. 2012; Butow et al., 2012). When questioned how he handled this linguistic challenge with the medical student, Pascal explained that in the days following his diagnostic appointment, he approached his Francophone family physician for clarification:

T'sais ça fait que...une semaine après j'ai parti pis j'ai été voir pour Docteur L " Oui, bin t'as pas eu tes résultats? ", j'ai dit " Elle me l'ai a donné, mais elle essayait de me le donner en français... " pis j'ai dit " ... j'a comprenais pas. " Je comprenais pas tout. C'est lui qui m'a aider. Qui m'a tout expliquer.

The use of a third-party in order to understand the information presented during the patient-specialist interaction was a frequent occurrence with participants of this study. In fact, studies have shown that clinicians themselves will sometimes use a third-party in order to more effectively communicate with their patients. However, the question of who this third party should be raises additional ethical questions that would not necessarily be present if the physician and the patient shared the same language. Tod Chambers (2008) has identified three primary forms of translation sources used by patients; namely, 1) professionals, 2) amateurs (outsiders with no relation to the patient) or 3) intimates (family members or friends). Of the

three, Chambers cautions that intimates of the patient can be the most perilous; both in making a medical diagnosis and in unintentionally raising moral issues since, in some instances, patients may be uncomfortable sharing sensitive medical information with intimates (Chambers, 2008). However, within smaller northern and rural communities where access to additional medical professional support, such as Pascal's family physician, is not always an option, several participants relied on other sources of support in order to help them process and understand their diagnostic information.

4.1.4 Accepting a Diagnosis of Prostate Cancer with Resilience

Several men, granted their recollections of how they felt when they heard the news of their diagnosis may have tempered with time, reported that they took the news with relative calm and resilience. Theoretical coding revealed that prior experience with serious illness, either personally or with a close family member or friend, familiarity with the health care system, and the presence of personal and social supports greatly influenced how these men approached their diagnosis of prostate cancer. For example, Bertrand Jr. accepted the news of his cancer diagnosis in a "matter of fact" manner; choosing to view it as a "speed bump" rather than a "road block." During our interview, he also acknowledged that being asymptomatic when he heard the news facilitated his optimistic outlook. When asked how he felt, he recalled:

Ça m'a pas traumatisé, et puis j'ai pas... j'ai pas arrêté de vivre, j'ai continué à faire tout ce que je faisais avant, comme avant. Parce que... j'me sentais pas malade. Non, j'avais pas de symptômes... euh... Et puis euh... après l'annonce j'me suis dit " Bin, j'suis pas plus malade aujourd'hui que j'étais hier... sauf que j'ai une condition qu'on va... on va s'en occuper.

Bertrand Jr.'s asymptomatic state facilitated his acceptance of his diagnosis since he didn't feel that anything had really changed apart from now knowing that he had a condition that he needed to deal with. When probed about his reaction, he continued:

Disons que... Ouin, fait que moi c'était pas... oui un certain choc, mais pas... euh... c'étais pas un... ça m'a pas jeté par terre. Ça fait un peu un petit choc là, mais pour moi c'était " OK, je l'ai... on fait ce qui faut. " T'sais, on va passer... on va suivre le processus, pis... on va... on va le régler, t'sais. Parce que... quand t'as un problème, il faut chercher des solutions. C'est mon attitude à moi là,

eah... ça donne a rien de garder le problème et puis le nourrir. Faut... quand qu'on tourne une page dans notre vie là... on l'a rapporte, on la retourne pas après là, on continue... on... t'sais. Euh... ça donne rien d'attendre, ça donne rien de... de t'sais, de se casser la tête avec ça... parce que c'est mieux de le régler. (...) C'est un épisode dans la vie de quelqu'un. Moi je... je parle toujours de la vie que... il a des " speed bumps " puis ça s'en est un, puis on l'a passé pis tu continues, pis le chemin est beau.

Bertrand Jr.'s account highlighted his resilience in the face of challenging circumstances. In this sense, his words described his intentional decision to make decisions and take actions based on these choices. In what Hitlin and Elder (2007) have termed *existential human agency* (Hitlin & Elder, 2007), Bertrand Jr. experience demonstrated his capacity to make sense of his prostate cancer experience by assigning meaning to it (e.g., a mere "speed bump" in his life path) that enabled him to process the information and make informed decisions regarding how best to handle his diagnosis within the social and historical context in which it occurred.

Éllie Jr. also expressed a similar reaction of acceptance towards his diagnosis of prostate cancer, which in turned also highlighted his own existential human agency and personal resilience in the face of the disease:

Personnellement, j'pense que personnellement j', c'était p'tit peut comme eh, t'a une infection au bout d'un doigt ça guérira pas, coupe le doigt, enlève l'ai t'sais. C'était ça ma réaction. Ça pas été de déprime ou eh de dépression aucune. C'était eh, eh, c'est un peu, les bobos arrive en vieillissant si y'a une façon, si y'a un moyen des guérir faite s'qui a à faire, c'est vous autre les spécialistes. Moi, j'suis l'patient. C't'un ptit peut ça que, qui était ma réaction à c'moment là pis encore c'est pareil aujourd'hui là.

Éllie Jr.'s response also pointed to the dynamic nature of his adaptation strategy in the face of his diagnosis. While functioning as an active participant within his illness experience, he also accepted to relinquish his care into the hands of his medical team. Éllie Jr.'s response was also mitigated by his view that medical issues are a normal part of aging. He explained, "*J'étais assez bien préparé mentalement et puis, ça pas été eh, un coup d'masse sur à tête là, c'était eh,*

un p'tit peu comme, écoute un peu a 73 ans, c'est normal que les maladies sorte." Germain and Jean-François, aged 65 and 75 respectively at the time of their diagnoses, also expressed an acceptance of their disease as a normal part of aging. Germain described prostate cancer as just another health issue that needed to be dealt with; while Jean-François viewed himself as "one of the lucky ones" because his cancer was detected in time to act upon it:

Ça t'donne un choc. Mais, euh, moi je grimpe pas dans les rideaux de rien. Là j'me suis dit, me suis calmer, j'y ai pensé sérieusement. Je me suis dit de c'tes années icites, y'en échappe beaucoup. Si j'chanceux j'va être dans s'gang là. Pis c'est ça qui est arrivé.

Élie Jr., Germain and Jean-François' respective accounts both point to a certain ambivalence they had regarding seeking additional information about their condition; partly because of their beliefs about the normal aging process and partly because of the trust they placed in the health professionals handling their respective cases. In fact, literature shows that when faced with cancer, some individuals choose to defer to their medical teams rather than source additional information (O'Rourke, 2001; Penson, 2012). Results from a recent qualitative study exploring the information and support needs of men aged 75 and older with a diagnosis of prostate cancer conducted by Bungay and Cappello (2009) demonstrated that the degree to which patients with cancer seek information about their illness depended not only on individual preferences for control, but also on patients' educational, cultural and financial backgrounds. In addition, authors from this study concluded that socio-economic factors impacted patients' ability to access health care resources, support and information, whereas cultural factors shaped perceptions of the meaning of illness (Harris, 1998). For Jean-François, adapting to his diagnosis was influenced by his need to share the news with those closest to him, fearing that the news would travel quickly within his small-town community and not wanting to disrespect those he loved the most by having them hear of his illness from someone else. He explained:

Ben, j'en parlais pas à tout l'monde, parce que c'tait pas un plaisir de n'en parler de d'ça. Mais avec ma famille, pis mes entourages. ...Puis j'en ai parlé à ceux-là, s'monde-là. Puis y'ont, y'ont compris ça eux autres aussi. Ben coudons. Mais, ça pas été une gloire de, de, de, de dire à aux autres. J'l'eux ai dit avant qui

l'sachent par les étrangers. Pis quand on a commencé avant, aller aux traitements, ben, y'étaient toutes au courant. Pis, mes enfants, on a trois enfants, pis les trois y l'savaient. Y'ont ben compris ça, y'ont ben acceptés ça. Pis ma femme à ben accepté ça. Coudons, on n'a pas l'choix.

The individual context in which the diagnosis of prostate cancer occurred played an important role in shaping how men recalled their experiences. As mentioned above, previous exposure to serious illness or to the health care sector was an important factor influencing participants' prostate cancer experiences. When asked about his reaction to his cancer diagnosis, Félix explained that while he was initially taken aback by the news, he did not panic: “*Euh, [pause] c'est difficile à dire. J'ai pas paniqué. Non, c'était pas une question de panique.*” When probed on why he thought he was able to remain calm upon hearing the news, he explained, “*Euh, ben j'ai une de mes filles qui, qui avait été opérer pour un cancer, donc t'sais c'était euh, c'était pas quelque chose de nouveau là, comme ça. Puis euh, j'savais quand même que c'était un, c'était un cancer qui s'traitait. T'sais.*” Félix's remarks acknowledged the larger context in which a diagnosis of prostate cancer is experienced. His comments also alluded to the fact that a diagnosis of prostate cancer often affects more than one person and its impact is felt by others; including men's friends, families and most importantly, their significant others.

4.1.5 The Partner's Reaction at the Time of Diagnosis

The potential distress that can accompany a prostate cancer diagnosis is often shared with a partner or spouse. In fact, prostate cancer is often considered a relational disease because its physical and psychosocial consequences can affect significant relationships, particularly intimate partner relationships (Galbraith et al., 2011; Sanders et al., 2006). Spousal reactions can therefore be understood as an important contributor to men's overall experience upon receipt of their diagnosis. Within this study, several participants shared information about how their wives reacted to the news of their cancer diagnosis; some which supported their personal resilience, and some that did not.

For example, Hébert explained that his initial shock was mitigated by his wife's acceptance of the diagnosis. Following their initial disbelief since he had been asymptomatic up until that point, her support and acknowledgement of his disease helped him accept it as well:

“*Moi ma femme l’a accepté, moi je l’ai accepté.*” This form of spousal reliance thus supported his positive adjustment to the disease diagnosis.

Quentin, on the other hand, shared a slightly different experience when he discussed his wife’s reaction to the news. While he recalled being calm and collected upon receipt of the diagnosis, he shared that his wife had a harder time accepting the news, “*Bin ça me... ça m’a pas dérangé trop trop là. Ma femme était au shopping centre à Timmins quand j’étais la rencontrer, pis là j’ai été lui dire ça, pis c’est elle qui commence à pleurer.*” When asked why he thought she reacted that way, he continued:

Bin un p’tit parce que elle, elle a eu un cancer du sein un avant eh, pis elle s’est faite enlevé un sein, pis elle a eu le chimo pis tout ça. Là bin moué j’ai dit ça de même, les docteurs m’avaient que... c’était opérable pis tout ça. Bin elle sur le coup bin... Ouin. Ouais, elle était plus sensible que moué ça fait que... Ouin, je pense que ça y’a fait plus quelque chose pour ma femme que moué. Ouin, parce que elle, elle pleurait souvent pis... ouin. Moué j’y ai jamais pensé réellement, au coton.

Bertrand Jr. also acknowledged that his diagnosis of prostate cancer may have been more worrisome for his wife than for himself:

Peut-être mon épouse pour elle c’était plus inquiétant d’une certaine façon, parce que là, t’sais... après, là ça fait 40 ans qu’on est ensemble, alors... à ce moment-là, 34 ans... t’sais bon bin, “ Il va tu être correct... ? ” t’sais, “ C’est tu sérieux son cancer? ” t’sais... parce que... en général, les dames s’inquiètent plus que les messieurs. (Rire) Je pense. C’était peut-être même plus difficile pour elle d’une manière. (...) Bin, j pense que... ça peut-être que ça l’inquiétait-elle aussi là. Parce que... parfois dans ces conditions-là, on oublie... on s’occupe du patient, mais on oublie de savoir... comment l’autre personne... comment l’autre personne... réagit, et puis comment elle se sent elle, t’sais.

The varying experiences shared in the above accounts demonstrate the need to promote resilience in both members of the couple in the immediate wake of a prostate cancer diagnosis (Docherty et al., 2007; Ezer et al., 2012; Friedman et al., 2012; Kershaw et al., 2008). In fact,

resilience among supportive spouses has been shown to facilitate a wide range of coping strategies that enabled men to deal constructively with feelings of shock, anxiety, uncertainty, grief and general psychological distress (Bonanno, 2004). Results from a study conducted by Ray and Street (2007) found that wives whose husbands had recently been diagnosed with prostate cancer undertook considerable emotional labour to facilitate their spouses' adaptation through a dynamic process of monitoring and adopting useful coping attitudes and strategies (Ray & Street, 2007). Thus, understanding the relational dynamics at the time of a man's cancer diagnosis is imperative to obtaining a comprehensive appreciation of this experience.

4.2 Selecting Treatment

Men diagnosed with localized prostate cancer can choose from multiple treatment regimens and are faced with an important decision in which both medical factors and personal preferences are important. Just as participants' reactions to hearing the news of their prostate cancer diagnosis generated various emotional responses, the processes men from this study engaged in to gather information and select treatment for their disease were diverse. In the following section, these experiences will be explored, and special consideration will be given to the unique geographical and linguistic complexities faced by Northeastern Ontario Francophone prostate cancer patients.

As previously identified in Chapter 1, there are multiple treatment options available to men facing a diagnosis of prostate cancer and most often, the risk category in which a man falls into will determine his choices for treatment (D'Amico & Smith, 2012). Generally speaking, low-risk patients are more suited to undergo active surveillance while men with an intermediate-risk cancer usually require intervention. For most participants within this study, intermediate risk-adapted cancer treatment options included surgical interventions (e.g. radical prostatectomy, brachytherapy or external beam radiation). Specifically, 16 of the 22 Francophone participants in this study opted for surgery (radical prostatectomy), three participants underwent external beam radiation therapy; two participants received hormonal therapy, and only one Francophone participant underwent brachytherapy as a treatment plan for his prostate cancer. It should also be noted that four of the study's Francophone participants received more than one of the treatments listed above. Typically, this involved being treated with external beam radiation and hormonal therapy; or external beam radiation in combination with chemotherapy. Participants who had

advanced diseases or were unable to undergo radiation or surgery were treated with hormonal therapies. It is also important to acknowledge that while some primary cancer treatment centres are now offering experimental cryoablation and high-intensity focused ultrasound treatments, these options were not available to this study's participants at the time of their initial diagnosis.

4.2.1 Looking for Treatment Information

Most participants in this study demonstrated a yearning to understand and know their options in relation to their prostate cancer disease. The process of information gathering and selecting a treatment course was as varied as the reactions expressed by participants upon receipt of the news of their diagnosis. Participants in this study shared a variety of accounts; from passively accepting the suggested medical treatment, to conducting extensive research on potential treatment plans and seeking multiple medical opinions.

For example, conducting extensive research and being well informed was paramount to Isodore. Upon receipt of his diagnosis, he purchased several books on prostate cancer but admitted to having some difficulty understanding all the information, "*J'avais acheté des livres là mais j'avais de la misère à me concentrer pis lire les livres pis comprendre un peu, les questions demandées aux médecins.*" As a result, Isodore chose to speak with other men who had faced a similar situation. He recalled:

J'avais parlé avec d'autres personnes. Après que j'ai été diagnostiqué là, j'ai euh... parlé avec différentes personnes qui ont... il avait un aide ici euh, [mon ami], il avait été opéré, à peu près une couple d'années avant moi, et... j'avais été soupé avec lui, pis on avait jaser de ça.

While some participants were actively researching treatment options, accounts from others pointed to a deferred decision-making process. While multiple treatment options were available for men with prostate cancer, therapeutic recommendations may have differed depending on the type of specialist they consulted. For example, Hébert, who was 56 years old at the time of his diagnosis, obtained most of his information from his family physician, who also happened to be one of his close friends. He stated, "*Moi c'est mon docteur qui m'a surtout, y m'a donné toute l'information vraiment. On était des grands chums. Fais que, t'sais, ça, ça l'a aidé beaucoup.*" Thus, based upon the recommendation of his family doctor, Hébert opted to have

immediate surgery. His deferral was an active decision to follow the medical advice of his family physician, a person whom he trusted most. When discussing his decision to have surgery, he expressed great frustration with others who “wasted their time” with alternative health care measures. He shared:

Les hommes qu’y’ont peurs, pis qui vont voir tout sorte de charlatans pourquoi qu’y perdent leurs temps. Ça j’aime pas ça. J’aime pas moi, m’a aller voir lui, mais là m’a faire si, m’a aller voir, parle des affaires naturelles. Pis ça finit là, ça passe au couteau. Que tu veules, que tu veules pas, si tu veux n’en finir avec tes problèmes. Pis ça j’aime pas ça. Quand j’les entends dirent non moi j’irais pas à ça, j’ai pas d’affaires faire si, pas d’affaires faire ça, ben. En tous les cas, tu feras c’que tu voudras, mais viens pas dire dans trois, quatre ans, j’aurais dû faire ça. Parce que m’a te l’dire. T’à toi d’écouter.

Hébert’s recollection pointed to the question of urgency and determination to be “cured” of his disease. Central to this account is the trust he placed in his family physician and his disdain for alternative forms of medical treatment. However, when later questioned on the results of his surgery, he admitted to having been shocked by the potential consequences of the surgery, especially in relation to sexual function:

Ça c’est, c’est ça qui m’a surtout frappé, toute les conséquences, toute que c’est qui peut, c’qui peut toute c’qui peut arriver dans vie là, t’sais. Parce que quand tu, tu t’fais dire qu’t’a l’cancer d’la prostate, quand t’es marié pis toute y’a, y’a une source qui s’produit là, t’sais. T’a pu la même vie là. T’sais, ta vie change, toute tes affaires change, qu’à temps tu t’viens revenu comme faut là. (...)T’sais, tu, tu réagis drôle. T’sais, j’avais juste (...)euh, cinquante-six ans.

Although immediate action was imperative for Hébert, he later acknowledged that his treatment decision posed serious consequences on his relationship. Referencing his wife and their relationship prior to the diagnosis, he shared that the potential sexual side effects of surgery were something that he didn’t fully explore since his most pressing concern at the time of his diagnosis was his need to rid himself of the cancer.

4.2.2 Consequences of Treatment Choices

Although Hébert described his initial shock at the potential consequences of treatment on his body and on his relationship with his wife, his initial decision-making process was largely based on the trust he placed in his family doctor's recommendation to have surgery. In fact, current literature indicates that while many men, like Hébert, fail to understand how the treatment for prostate cancer could impact their quality of life, many do not seek further information beyond that which is provided during initial consultations (Bungay & Cappello, 2009). Like many men interviewed as part of this study, Hébert believed that his primary care doctor possessed the knowledge to treat and make educated decisions on his behalf; without a complete understanding of the implications of these decisions on his overall quality of life. His statement that he was "just fifty-six years old" at the time of his surgery further highlighted his belief that treatment consequences related to sexual functioning were age-dependent rather than treatment-based risks.

Another participant, Napoléon, also chose to follow the treatment recommendation of his urologist. However, his decision to opt for surgery was primarily fuelled by his fear of the consequences of delaying treatment as his close friend had done. He recalled:

*Bin là ça m'a fait peur un peu. Lui je savais, ça faisait une secousse qu'il m'en parlait qu'il l'avait, mais il faisait rien... t'sais... lui il a rien fait, il a attendu en dernier de tout, ça fait que là il était trop tard. Ça fait que j'ai dit " Si je fais pareille moué..." t'sais... peut-être que ça l'aurait pas faite ça itou là. Ça l'agit pas pareil sur toutes les personnes je cré bin. Ça fait que c'est ça qui nous a poussés un peu à aller pour l'opération t'suite. Ça l'a des conséquences, mais coup donc! Comme moué j'te dis, moué j'étais un peu craintif, des fois tu te fais suivre, pis là il prend un test pis là *oops* tiens là ...il est trop tard. Ça fait que... je voulais en finir avec t'suite. Je savais qu'il aurait d'autres conséquences après là, mais t'sais... coup donc... (Rire).*

Stéphane also believed that undergoing a radical prostatectomy was his best option since any account of recurrence could then be treated with radiation therapy. He explained how this "safety net" helped him contain his fear and anxiety over the potential consequences of the procedure. He shared:

En prenant l'opération, si ça recommence, t'as une deuxième chance, tu peux aller à radiation. Fait que, j'ai eu beaucoup de bons conseils, que je trouvais qui était réconfortant, des choses comme ça. Comme j'avais une deuxième chance souvent. Ça fait que, c'est toujours... c'est sûr qu'on n'a, on n'a pas le choix, on l'a pis il faut dealer avec, mais on peut aller chercher les deuxièmes chances, de quoi qui va nous réconforter, qu'on a toujours espérance...

For another participant, Jean-François, avoiding potential side effects was a primary factor in his decision to have radiation therapy. After having witnessed his neighbour's pain and suffering from multiple complications after undergoing a radical prostatectomy, he refused to go under the knife. When further questioned on his treatment decision, he offered an age-based rationale:

J'avais soixante et cinq ans. Y dit, passé soixante, euh, présentement après les traitements, t'es garantis pour dix ans. Pas aucun problème. Passer dix ans, le cancer progresse pu, passer soixante et dix. Y dit, tu peux rester au même stage pendant dix, quinze ans ça change presque pu. Fais qu'y dit, tu vas tomber soixante et dix, soixante et onze, si jamais ça reprends.

Another participant, Onézime, described his treatment selection process as one of learning since he admitted to knowing very little about prostate cancer prior to his diagnosis. He recalled:

Je me suis informé après que j'ai été diagnostiqué. J'ai une encyclopédie médicale. Il est un peu um... elle date de 1964, mais c'est français, pis la médecine en Europe est en avant de la nôtre. Fait que t'sais c'est pas mal... t'sais. Ils parlent de, de, des traitements de radiographie, d'hormonothérapie. La radiographie bin c'est considéré pour eux autres comme... pas tellement efficace. Ils parlaient de traitements de l'hormonothérapie c'est... ça vient de 1940. T'sais, ils sont aperçus que... les, les hormones mâles, ça prenait la testostérone pour faire... profiter pour grossir la tumeur pis on me dit là-dedans, ils ont essayé la castration pis ça pas marché parce qu'il a deux autres glandes qui sécrètent là, t'sais (Rire). Pis ils ont découvert ça là, fait qu'ils ont, ils ont pensé aux hormones féminines. En donnant des hormones féminines, peut-être

ça va faire descendre l'autre, pis justement, c'est pas le cure, mais ça prolonge la vie. T'sais j'ai encore le, le roufale des hormones féminines là (Rire) ceux là qui démolissent un homme au coton là...

For Onézime, his decision to accept the hormonal treatment plan recommended by his physician was made with full disclosure. Having conducted intensive research, he understood that the adverse effects of androgen deprivation therapy were a consequence of the induced sex steroid deficiency and could include issues related to impotence, hot flashes (caused by dropping testosterone levels), breast growth and tenderness, as well as other possible side effects linked to longer term treatment exposure such as weight gain, memory problems, mood swings, depression, osteoporosis and an earlier risk of heart attacks (Casey et al., 2012; Hammerer & Madersbacher, 2012; Morgentaler, 2013; Rick et al., 2013; Sevilla, Maliski, Kwan, Connor, & Litwin, 2012; Walker & Robinson, 2010). However, Onézime's proactive approach to understanding the potential side effects of his treatment plan helped to alleviate much of the fear and frustration he could have experienced. In his own words, he explained:

J'étais bien préparé en avance (Rire). Il n'avait pas de surprises quand qu'ils me proposaient un traitement, je le connaissais, je le savais. Ouin, moué c'est ça t'sais, j'suis un liseur compulsif (Rire) ça fait que... ça l'enlève des craintes t'sais. Il n'a pas de surprises, il a moins de surprises, ça l'enlève des craintes, t'sais. Bin qu'est-ce qu'ils vont me faire, qu'est-ce qu'ils vont me dire, ah non, quand tu le sais d'avance... t'es prêt.

Having conducted his research prior to meeting with his specialist, Onézime felt as though he was equipped with the information he needed in order to make an informed decision in relation to his disease treatment plan and to handle any consequences that may present themselves as a result of these decisions.

4.2.3 The Spouse's Role in Treatment Selection

While being aware and being prepared can certainly facilitate men's adaptation to the possible side effects of prostate cancer treatment; it would be remiss to insinuate that only men are affected by these negative consequences. Treatment side effects, including urinary incontinence, erectile dysfunction, loss of libido, and fatigue affect not only the patient but also

his partner or spouse and as such, can dramatically alter their personal relationship and further affect the quality of life of a couple (Harden et al., 2002). As such, it is commonly expected that patient's spouses or partners will play a significant role in the treatment decision-making process. In fact, many physicians formally request spousal attendance during diagnostic meetings and follow-up appointments where treatment options are discussed (O'Rourke, 2001).

The role of the spouse as a support, resource and intermediary has been well documented in the medical literature (Boehmer & Clark, 2001a; Boehmer & Clark, 2001b; Mishel et al., 2009; O'Rourke, 2001; O'Rourke, 2007; Schumm, Skea, McKee, & N'Dow, 2010) and the accounts presented in this study supported these findings. For example, Hébert, who had been married for 34 years at the time of his diagnosis, explained how he felt that his wife's training as a nurse facilitated their understanding of his treatment options:

Parce que dans les thèmes de médecines euh, tu comprends pas toute. Ma femme est garde-malade, à comprenais plus que moi quand on a eu des informations, à savais un peu c'que sa voulait dire, moi j'savais absolument rien de d'ça là.

Another participant, Quentin, also admitted that his wife was the primary researcher when he was diagnosed with prostate cancer, stating, “*vraiment ma femme elle a faite sur l'Internet là. Elle m'a donné des affaires à lire, mais j'ai pas lis beaucoup là-dessus*”. Isodore also spoke of his wife's involvement in his treatment decision-making process when he shared that:

Ma femme est... est venue avec moi voir le médecin. Parce que je m'en rappelais pas toute de ce qu'il me disait. Mais euh... mouer j'aurais laissé ça “ watchful waiting ” ... Elle avait compris qu'un Gleason score de 7.5, c'était... c'était assez agressif. Agressif.

Quentin then recalled how his adult children also influenced his treatment decision:

Ça fait que mes enfants et puis ma femme, ils m'ont dit “ Fais-toi opérer. Ils voulaient pas... ils voulaient pas que je meure du cancer. Il voulait que je sois encore icitte pour en parler pis... j'avais des petits enfants moi, qui étaient très jeunes...

When asked about his initial hesitation in the face of his family's insistence on surgery, Quentin admitted that while he was scared of the side effects of surgery, his wife and children were more afraid of losing him. He told of her saying, "*Ça va se répandre, pis ça va être pire. T'es mieux d'avoir des effets secondaires pis être capable d'en parler (Rire) que de regarder les pissenlits pousser par la racine! (Rire)*".

For many participants, their immediate reactions and decisions were based on their desire to live, despite the potential consequences of treatment on their quality of life.

4.2.4 The Consequence of Choosing Surgery on Sexual Function

The most commonly feared consequences of prostate cancer treatment relates to men's sexual functioning. In fact, many participants shared that their treatment decisions were primarily based on the potential impact of their decision on their ability to maintain personal relations with their spouses or partners. Even in the case where surgery was strongly recommended, some men felt incapable of making the final decision because of their fear of impotence and erectile dysfunction. For example, Doménic shared how logically he understood that the surgery was "his only option" yet emotionally, he could not bring himself to agree to it. Wanting to "remove" the cancer but fearing the possible sexual consequences related to surgery, he turned to his wife to decide what "they" should do. Doménic recalled:

Là ben, rentre dans l'office avec moi pis ma femme, commence à donner des options Y dit, " I could give you radiation but " y dit, if it ... lui est Anglophone, c'est pour ça j'te parle en anglais. Y dit, " if it doesn't work, I won't be able to operate anymore, because, cause of the radiation ". Une fois qu'y dit à ça On pourra pas l'opérer. " Or I can give you hormone treatment " y dit, " but usually I give that to ... " j'donne ça à des personnes que c'est plus âgées. Ok, parce que ... Y dit, à ton âge moi là là y dit, j'irais pour la ... j'sais pas comment appelle ça là, enlever la prostate. Ouin. J'y dit, okay. Mais euh ... pis la y dit ben, " it's a lot ". Okay, parce que moi j viens juste de m'faire dire que j'ai le cancer. Fais qu'si qui y'enlève ça, ya va enlever le cancer. J'ai dit, okay, passes-y. Y m'dit " there's something else involved " y dit " you have to discuss this with your wife, cause " euh, j'sauverais pas ton nerf erectile, peux pu avoir d'érections, ça fais que, ta sex life là... Ben sais j'ai dit okay, parce que j'disais à moi-même

j'viens de m'dire que j'ai le cancer, comme j'ai mis ça de côté moi là, j'ai balancé les affaires... pis là j'parlais avec ma femme, pis j'dis qu'est-ce qu'on fait là? Pis elle dit j'veux t'avoir encore, est avec moi une secousse, euh ... c'est ton choix, mais tant qu'à moi j'aimerais mieux que t'sais ... de t'garder que... J'dis okay. Mais là t'sais... [inaudible] mais après ça là. Une semaine, deux semaines de même ça s'injecte tout dans la tête. So, anyways, j'fais ça.

Doménic's admission of the difficulty he endured in making the decision to have surgery at the expense of his sexual function speaks to the heart of the issue experienced by many men when faced with the burden of treatment selection. In fact, it has been well documented that maintaining sexual function remains a main concern for a majority of men facing prostate cancer, who often continue to be interested in sex after treatment (Colson et al., 2012; Flynn et al., 2012; Klaeson et al., 2012; Namiki et al., 2012). Current research suggests that both men and women remain sexually active well into their 70s and 80s (DeLamater, 2012) and while several preventive and treatment strategies for the preservation and recovery of sexual function from treatment for prostate cancer are available, there currently does not exist any specific recommendations or consensus guidelines regarding the optimal rehabilitation plans or treatment protocols (Chung & Brock, 2013). Given the potential impact of one's treatment decision on their physical and sexual quality of life, many participants admitted to being unable to make the final decision themselves. Napoléon, for example, shared how he and his wife jointly reached a decision to have a radical prostatectomy. He recounted:

Bin, comment qu'on a géré ça... on a discuté à propos du cancer, si on fait rien pis... si on le découvre, bin si on attend trop tard bin des fois on le sait pas. Je me fais opéré pis j'ai attendu trop tard pis là c'est répandu partout bin... On a recalculé qu'on avait des meilleures chances à le pogner drette au début.

Another participant, René, also shared how his wife was heavily involved in his decision-making process. While René was mostly preoccupied with the possibility of loss of sexual function, he shared that it was his wife's insistence that his life was more important than their sex life:

On a cherché, on a fait des recherches euh... on a regardé dans des livres... les livres, les livres sur les cancers c'est des livres qui sont pas toujours à point, par

le temps qu'ils sont imprimés, il a déjà d'autres choses de sorties. Ça fait qu'on est... c'était bin dur d'être capable de, c'est dur d'être capable d'avoir... l'aspect sexuel, mettons, après... Pis après ça je pense qui a bin des hommes... qui veulent pas le savoir. T'sais j'veux dire... quand tu te fais dire ça là... que tu perds toute ta virilité là... euh... à 95, 98 ou 100 % là... c'est dur à prendre aussi. T'sais, il faut pas... il faut pas que tu mettes ça en ligne de compte... en prenant ta décision. C'est pour ça que c'est elle (sa femme) qui a pris la décision, parce que moi si c'était aînque de moi là, probablement j'aurais dit bin, on va essayer d'autres choses avant l'opération. Mais quand qu'elle dit elle là là... on va pour le maximum tout de suite t'sais... t'sais c'est pas, c'est pas... on... le sexe c'est pas 24 heures par jour, 365 jours par années, ça fait que... mais on vit 365 jours.

René's wife's concern for his survival also took precedence over his fear over the potential loss of his virility. When probed, he admitted that she was the final decision maker. He explained:

Le docteur y me... il m'avait dit... t'sais, des affaires qui m'a dit que... moi... c'était tout parti. Pis là là, bin quand il vous a dit, il test les opérations là, là moué je savais pas au juste qu'est-ce que... quessé faire. Là c'est elle, c'est P qui a pris la décision, elle a dit... Pis là il avait expliqué que les effets secondaires sont bin plus sérieux quand que c'est le... l'opération que quand que c'est les autres affaires. Au point de vue sexuel pis tout ça là t'sais. Mais là, elle dit " Non... (Il se remet à pleurer)... ça, ça compte pas" elle dit " Il faut tu gardes... c'est la vie qui est importante". Ça fait qu'elle a pris la décision... c'est elle qui l'a pris avec moué. Non, c'est surtout elle qui l'a pris.

Sexual dysfunction can cause ongoing emotional distress by reinforcing negative body image (DeFrank, Mehta, Stein, & Baker, 2007), disrupting relationships (Galbraith et al., 2011), and reminding patients of their cancer experience (Hart et al., 2008). In addition, as highlighted in René's account, some men also experience a fear of abandonment when faced with treatment decisions that could impact their sexuality and/or virility. When probed as to why he thought some men feared that their wives would leave them, he explained, "*Mais ça c'est un, ça c'est un côté que après qu'un gars a perdu de sa virilité, son sex drive, que il a énormément peur que sa*

femme le laisse. Ça c'est des choses qui arrivent! ” Within this relationship dynamic, René's wife's involvement in his final treatment decision allowed him to mitigate some of his fears by shifting the accountability for future consequences to her, “*Moué ça pas été difficile, moué j'avais pas voulu le prendre, c'est elle qui l'a pris à ma place. Ça fait que... Là aujourd'hui si elle me laisse à cause de ça là, m'a dire que c'est de ta faute (Rire)*”. In this light, the shared decision-making allowed the couple to also share the implications of their joint decisions.

4.3 Receiving Treatment – A Northern Experience

Participants in this study described the different processes they engaged in when gathering information and making a final treatment decision in relation to their prostate cancer diagnosis. Their ultimate decision was influenced by a myriad of factors including, but not limited to, survival estimates, the potential side effects of each treatment option, beliefs about cancer and cure, personal or vicarious cancer experiences, as well as the social and medical contexts surrounding their diagnosis. Similarities existed in areas such as their need to gather information, the role of their spouses and the influence of different geographical and linguistic considerations on their treatment selection process.

Given that advanced treatment for prostate cancer is not available in many smaller, more rural communities in Northeastern Ontario, participants in this study were often required to travel long distances in order to access specialized health care services. For example, Quentin's account of multiple-city trips typified what many participants experienced upon receipt of a diagnosis of prostate cancer. In describing his journey from diagnosis to treatment selection, Quentin shared his account of visiting three different specialists in three different cities:

Bin, le docteur m'avait que... t'sais soit opérable ou... on avait discuté ça un peu, pis il était pour me revoir après. Ça fait que après ça, bin il m'a rencontré ici un mois après, après ça il m'a envoyé à Sudbury, pour voir un autre spécialiste pour... pour voir si ça serait mieux... Comment que t'appelles ça là? De la radio. Pis là, là-bas bin... il m'a examiné pis après ça ils ont dit l'âge que j'avais, pis je feelais bien pis tout ça, de... d'aller pour une opération. Pis là en revenant de Sudbury, j'ai arrêté à Timmins, pis là Docteur m'a rencontré pis il a fait le rendez-vous à Toronto.

Since travel was such an inherent part of the treatment decision process, selecting where to have treatment was an important consideration for most participants in this study. In fact, several men explained that their treatment options were presented to them in geographic terms, rather than in terms of the treatments themselves. To this end, their treatment selection decisions were made in light of additional considerations such as travel distance to the treatment centre, familiarity with treatment locations (e.g., cities in general, and treatment facilities in particular) and the presence of family or friends within host treatment communities. In addition, several participants stated that the availability of French language services was an important consideration in their choice of where to seek treatment. In fact, in certain cases where either the participant or his wife was unilingual French, this factor superseded all other considerations.

4.3.1 Travelling Far Away in Order to Obtain Medical Services in French

Recalling his decision to opt for surgery, Félix shared that multiple factors, including language, influenced his final decision on where to seek his treatment. He shared:

C'est parce que là j'venais d'avoir le, je revenais de Timmins, puis j'avais le, le diagnostic et j'avais euh, Ottawa ou ben Toronto parce que Sudbury je l'avais laissé d côté, parce que moi je n'voulais pas allé à la radiation, du moins pas en premier. Alors, puis, Toronto ça m'disais rien. Euh, mon épouse vient d'Ottawa, mes enfants étaient à Ottawa, donc, t'sais j'tombais pas dans un milieu où on est... Pis, en allant à Monfort ben c'était francophone. Donc c'était toutes des facteurs.

Upon further discussion, Félix also shared that his decision to seek treatment in Ottawa was very costly; both monetarily and in time spent travelling. He described having travelled to Ottawa during four separate car trips prior to his surgery and another 6 times post-surgery due to various complications. He explained that each trip took an average of twelve hours, one-way. When probed whether he had accessed any of the funding programs available for people living in Northern Ontario, such as the Ministry of Health and Long-Term Care's Northern Health Travel Grants, Félix shared that his initial applications to this program had been denied. He clarified:

J'ai dus euh, avoir euh, entreprendre certaines démarches cependant, parce que le Ministère d'la Santé refusais de payer, de me payer les frais de déplacements pour aller à Ottawa, y me payait pour aller à Timmins. Pis quand ça fait dix

voyages que tu fais, ça commence à couter cher. Alors euh, alors un moment donné j'ai rencontré le Dr.X., puis j'ai dit " Dr X., si j'écris une lettre au Ministère d'la santé ", parce j'avais écrit, y m'avait répondu ben, non ta lettre ne vaut rien, faut ça soit ton médecin qui écrive. Alors, j'ai dit " si j'écris une lettre, puis j'la prépare. Si j't'la donne est-ce que tu pourrais la relire, vas-tu la signer et l'envoyer? " Y dit, " probablement ". Alors, j'ai écrit une lettre, j'ai, j'suis revenu sur toute les étapes, les voyages que j'avais dû faire et l'dernier paragraphe que j'ai écrit, j'pense c'est ça qu'y'a changer, j'ai dit, peu importe tout c'qui précède, c'que je désirais, c'que je voulais c'était traiter par un médecin francophone dans un milieu francophone. Et trois semaines après j'avais six chèques qui rentraient.

Félix's account of writing a formal complaint letter, in French, demonstrates the level of advocacy that some patients were required to do in order to obtain funding to access services in their preferred language. Accessing French-language services was also important for Moïse, whose limited knowledge of the English language did not include proficiency in medical terminology. Although he asked his specialist to bring in a French-speaking nurse to translate the English information he was being given, his urologist refused stating, "*J'ai pas besoin de nurse pour faire mes affaires.*" Recalling how upset he was by this, Moïse shared that he then went to see his family physician in order to obtain a referral to another specialist. He recalled the following reaction:

J'y ai expliqué ça, pis il m'a donné la main pis... j'ai dit " T'sais mon homme... " j'ai dit " Je le comprends pas à moitié, de quessé qui dit " pis là il m'a transféré, il dit " J'm'en va... " il dit " Si tu veux avoir du service en français... " il dit "... il faut que tu ailles à Ottawa ". Ça fait que ... c'est de même que ça l'a continué.

Another participant, Hébert, shared of his 'good fortune' when the specialist he saw was able to speak French. When asked how he thought this affected his overall experience, he shared:

Oui, très important. Parce que dans les thèmes de médecines euh, tu comprends pas toute. Ma femme est garde-malade, elle comprenais plus que moi quand on a eu des informations, à savais un peu c'que sa voulait dire, moi j'savais absolument rien de d'ça là. Oui, moi c'est au côté de d'ça, pour moi

personnellement là, tout l'temps que j'ai été malade, j'me suis faite opérer, j'ai pas eu d'problèmes de langue. Ni un bord, ni d'l'autre. J'ai tout l'temps eu, j'ai tout l'temps eu c'que j'ai voulu. J'ai tout l'temps demander c'que j'voulais, pis y vont tout l'temps répondu.

Another participant, Jean-François, obtained treatment in a predominantly Anglophone centre. He revealed that the free in-house translator services that were provided at this centre helped him understand the information he was being presented:

Ben, euh, y'avait pas beaucoup d'français dans l'hôpital là. Mais quand que j'avais d'besoin de, dans la médecine c'est des termes difficiles à comprendre, qu'on est pas habitué, y'a du personnel français que j'pouvais avoir. Gratuitement par la province. Au début là, j'avais toujours c'te madame avec moi. Puis, y n'avait deux, même. Puis après ça, là, pour les journées des traitements, j'tais correcte, j'm'arrangeais ben. Pis les 'tites filles qui travaillait là t'est ben correcte aussi, puis. (...) J'ai pas souffert de d'ça. Avec le peu que j'savais, eux autres m'aidait.

Accessing support systems, either formal or informal, was also an important factor in many participants' treatment location decisions. Onézime shared that his decision to obtain his hormonal therapy in Sudbury was primarily based on the fact that most health care staff were bilingual ("except for the specialists") and because he had family living within the city. Having access to family within the community allowed him to stay with them during the weekends when the hospital housing was closed. Since his treatment plan was seven weeks long, the ability to stay with his family saved him a lot of travel time and money. He shared:

J'ai de la parenté dans le coin...des beaux-frères, des belles-sœurs. Fait que non, non, j'ai aimé ça. J'ai aimé, t'sais, parce que...J'ai pas du voyagé, j'ai été là sept semaines, j'ai été là sept semaines. J'aime pas voyager, pis j'suis pas capable d'y aller par moi-même...j'ai pas le sens de la direction, pantoute! Pis j'ai resté là tout le temps, toute la période de sept semaines. En fin de semaine si je restais au Pavillon des jonquilles, vendredi après-midi il faut sortir de là, ça fait que ma belle-sœur venait me chercher pis...Ils venaient me ramener le dimanche. Ils ont été bin bin fins. Bin bin gentils.

Initially, Doménic had also selected his Northeastern Ontario treatment location because of the support available to him from his adult children living within that community. However, because of the long wait time to have his surgery at that facility, he chose to travel to Southern Ontario for treatment in order to expedite the process. He explained:

Fais que j'contacte le médecin à Sudbury. Fais que j'ai toute l'information, mais y'est occupé. [Mon spécialiste] revient [quatre mois plus tard], pis comme de raison chaque fois qu'y venait, ben faisait prendre un 'prostate specific antigen' test. Fais qu'là ça avait augmenté comme de raison. Y dit, " what's going on, how come you didn't have surgery yet? " J'y dis, well he's, he's busy, toute ça t'sais. Y dit, " well, your cancer is spreading because your PSA is going up " comme si y'avais augmenté. Oh ya? Y dis " it's up to you but " y dit " I wouldn't wait ". Y dit " I could have you on the operating table by the end of the month ".

For Doménic, accessing timely treatment superseded all other considerations, and ultimately influenced his overall prostate cancer experience.

4.3.2 The Need for Translators in Large Anglophone Health Care Centres

For many participants in this study, receiving treatment for their prostate cancer was a time shrouded in anxiety and uncertainty. Having opted for surgery in Hamilton based on the positive experiences of two of his friends; Éliam used an analogy of being in a “slaughter house” to describe how he felt on the day of his surgery:

Ça m'a impressionné un peu quand que j'ai arrivé, vu que c'était toute en anglais... On était huit en ligne là... ça faisait sembler à un abattoir, tu resterais surpris, les nurses, ça passait avec les charriots de même et puis ils te mettaient les, les aiguilles dans les bras et puis tout ça. (Rire) J'ai dit " tabarnouche, j'ai quasiment pas envie de me faire opérer icitte " (Rire) J'ai dit " ça va trop vite ça là icitte c'est impressionnant! " Pis là bin vue que je ne parlais pas en anglais bin bin pis j'ai pogné une nurse qui était pas parlante elle... j'y ai posé deux, trois questions et pis elle me répondait pas en voulant dire " Pause mouer pas de questions! " (Rire). Ça fait que... pis ça, elle dit, au bout d'un heure ils sont venu me chercher, ils m'ont amené dans le passage, ils m'ont dit " Tu vas être le suivant sur la liste" m'a être... on était huit en ligne là, ça faisait sembler...

c'était comme une chaîne... J'étais le troisième ce matin-là qui était... qui se faisait opérer. Seule chose je l'ai revue là j'ai dit euh... dans la chambre d'opération j'ai vu tout de bin une minute et puis, ils m'ont tombé en dormis et puis je l'ai revue [le spécialiste], je l'ai revue une journée avant que je sorte de l'hôpital.

Éliam's account made reference to how things are done quickly in a big health care centre. Several participants, himself included, alluded to the increased anxiety caused by the speed of the process once they became part of the health care system. Since the culture of care in many smaller communities often necessitates a more relaxed, informal approach to symptom management, Northern patients who find themselves within high-volume practice centres are often taken aback by the speed of the process in larger cities. In this case, while Éliam admitted that accessing more timely care was a determining factor in his decision as to where to seek treatment, he later divulged that opting for treatment in an English facility was also a cause of increased anxiety. He shared:

Oui ça c'est... c'est inquiétant un peu tu sais... tu sais pas vraiment quessé... tu réponds à peu près... il avait des questions... il n'a la moitié que j'étais capable, que je savais ce qu'il voulait dire... mais... des fois, mais au lieu de le faire répéter une troisième fois, mais tu disais ou non (Rire) tu sais... C'est ça que j'ai... que j'ai pas aimé de... la première chose... il devrait avoir un interprète quelque chose, que tu peux rencontrer.

Éliam's expressed need for greater access to interpreters within culturally and linguistically appropriate health care services has been echoed in recent literature (De Maesschalck, Deveugele, & Willems, 2011; Dias, Gama, Silva, Cargaleiro, & Martins, 2011; Harmsen, Bernsen, Bruijnzeels, & Meeuwesen, 2008; Komaric, Bedford, & van Driel, 2012). However, the reality of the current state of Northern Ontario's health care delivery model does not lend itself to meeting the needs of all patient populations. When further probed on how he managed to deal with the language issues when seeking treatment in an Anglophone health centre, Éliam explained that his son was often required to play the role of intermediary between himself and his specialist. He shared:

Euh... Ça, c'est ça qui est... euh... qui était difficile parce que quand que je suis allé à Hamilton euh... anglais je me débrouille parler comme, de même là, mais quand dans les termes de... médecine... C'est... c'est pas facile. C'est pour ça que j'ai été obligé d'amener mon garçon avec moi pour avoir un interprète euh... là-dedans. Pis euh, je les avais demandés s'ils avaient des interprètes là, ils m'ont dit non.

While Éliam shared his gratefulness towards his son for acting in this intermediary role, he also expressed his discomfort at requiring this type of assistance from his son; especially given the sensitive nature of prostate cancer in relation to male sexual function. As previously mentioned, the use of translation services from family members or friends can force the patient and the translator to face uncomfortable situations (Chambers, 2000; Chambers, 2008). In addition, as stated by Chambers (2008), these types of non-professional translators can sometimes inadvertently add or subtract relevant patient information during the informal translation process.

The location of treatment and the language in which one received said treatment was also seen as a contributing factor to participants' post-operative experience. For example, Hébert spoke of the personal hardship he endured when he had his radical prostatectomy. He shared that a three-day post-operative recovery period was extended to two weeks because of surgical complications:

Ça été euh, j'ai trouvé ça dure. J'ai été quatorze jours à l'hôpital. J't'ai supposé d'sortir dans trois jours pis j'ai pas sortie, j'ai faite une, j'ai faite une réaction. Le cœur a partie en peur, en t'es cas là [inaudible] après avoir été opérer. M'avait faite piqué, euh, gelé j'veux dire. Pis j'suis faite endormir, ben dans nuite d'l'opération j'ai faite une réaction. Pis là y m'on descendu en bas passer des ultrasons, pis passé toutes sortes des check-up. Pis quand j'suis revenu la garde-malade a dit, ça va revenir, pis là j'avais compris que, mets qu'y m'enlève ma, l'aiguille qu'y t'mettent là, t'sais? [inaudible] dans vingt-quatre heures tu devrais revenir, fais qu'c'est revenu, mais mon cœur a manqué, j'avais plus de sang, euh, manquais d'sang avec le bord pis toute ça. J'ai été quatorze jours à l'hôpital après ça chu retourné à la maison.

While all patients are made aware of the potential consequences prior to undergoing surgical treatment for prostate cancer, Hébert's extended hospital stay also translated into a prolonged separation from his personal and social supports which only further exacerbated his anxiety and discomfort.

4.3.3 Discomfort and Incontinence: Consequences of Treatment

Most Francophone participants in this study were required to travel outside of their home communities for treatment for their disease. As mentioned above, for many, these decisions on where to have treatment were as important as which treatment to select. However, regardless of what treatment they opted for, many participants spoke of the challenges they experienced following treatment.

As previously mentioned, Hébert was required to extend his hospital stay by two weeks when he experienced several post-surgery complications. When probed about the most difficult part of his overall surgical experience, he shared of the difficulties being away from "home" and described his struggle with the unreliability of his body.

Calling this period a "return to infancy," he shared:

L'affaire j'ai trouvé dur là, c'est quand que tu deviens comme enfant là. Tu tombes en enfance, tu t'fais opérer, tu deviens là. Pis là la garde-malade m'avait dit quand j'ai commencé à manger, faisais, j'ai été une dizaine de jours sans manger. À dit, t'à l'heure du avoir, faut t'y'ailler à chambre de bain pis toute, pis tu sauras pas, à dit. Ça s'est faite dure ça. T'sais, quand t'arrive, tu tombes en enfance là. Les premières fois là, t'es pu là. Arrivé là, pis tes besoins, t'habitués d'avoir la chambre de bain pis toute, pis tu t'échappes là. Ah, ça là, ça sa m'avait abattue ça, ça m'avait ... Pis ma femme a dit voyons, a dit t'est pas l'premier tu seras pas l'dernier. La garde-malade arrive, a dit arrête-moi ça, a dit voyons dont. (...) Arrête ça a dit, aye, on a vue de d'ça avant aujourd'hui, à dit, j'te l'avais dit ça arriverait. Pis ça avait arrivé sur l'heure du midi. Pis y'avait d'la visite dans chambre. Ah j'étais, ça sa m'avait choqué, ah! [rit] J'étais assise dans une chaise, on mangeait, pis on avait du fun, ah, ça sa m'avait assez

découragé. Ben, c'est pas toi qui contrôle ça. Pis c'la maladie, pis faut t'apprenne à vivre avec ça.

Living with the consequences of treatment was a humbling experience for Hébert. Exhibiting signs of a “second infancy” led him to re-evaluate his self-worth while living within a new set of circumstances that he could not control. Hébert’s account also pointed to the important supporting role his wife played during his treatment process.

Several participants spoke of the anxiety they faced when trying to make the best possible treatment decisions, while fearing the potential consequences that could stem from their therapeutic choices. For Onézime, his decision to undergo hormonal therapy was also a way to avoid some of the potential negative consequences of surgery, such as those described by Hébert above. While his specialist recommended surgery, Onézime’s fear of incontinence prevented him from taking that treatment path. He explained:

Ils disent le meilleur traitement, si c'est diagnostiqué assez jeune, c'est l'hormonothérapie et chirurgie. Mais j'en connais, j'ai rencontré des jeunes qui ont été, qui ont été opérés, qui ont subi la chirurgie, ils sont in... ils sont... t'sais, ils ont pu de retiens bin, ils urinent dans leur... et puis, ça pas fonctionné. Pis j'en connais un autre, il a été opéré lui (...) deux mois après que j'ai eu fini mes traitements à Sudbury, il a été opéré, mais il fallait qu'il retourne en traitement, il a subi des traitements de radiographie pareil comme moué. Pis il était opéré, ça fait que ça donne pas grand-chose l'opération. D'après ce que je peux voir là, je sais pas mais... Ça me dit pas grand-chose l'opération moué là là, avec les p'tites expériences de même que j'ai eues là. Je regardais l'anatomie de ça là, t'sais, l'urètre passe drette dedans là, ça fait que c'est dangereux ça. Il a rien qu'à coupé un p'tit plus là, pis... t'es obligé de porter un sac.

However, Onézime’s experience was not free from side effects. When asked about how his body took to the hormone treatments, he described several serious consequences, “[J’avais] la myalgie, asthénie, uh vertige, perte d’équilibre, (...). Au début ça faisait beaucoup. Pour deux semaines après l’injection j’étais obligé de me tenir après un mur pour aller à toilette la nuit”. While the side effects he experienced were physically demanding, Onézime’s wife and family

chose to act as though he was not sick. While denial is not necessarily conducive to recovery, Onézime described it as being a constructive strategy:

Quand j'ai dit ça à ma femme, tout ce qu'elle a fait... " Ah! " Et puis le reste dans famille ils ont agi comme si y avait rien. Comme si y avait rien, t'sais. Ça l'a été plus facile je pense à cause de ça. T'sais, c'est comme si rien avait arrivé pis, j'étais pas malade. Moué j'me sens pas malade. J'ai juste, j'ai perdu beaucoup de forces physiques là, à cause des traitements. C'est les traitements qui sont durs. Les hormones de femme sur un homme là, ça fait dur. C'est dur mais j'ai agi comme...comme si y avait rien. Ça fait que ça m'a amené à agir un peu comme si y avait rien.

Several participants in this study described the physical and psychological challenges they experienced when receiving treatment for their prostate cancer. Léopold, on the other hand, offered a unique and opposing account of his treatment experience. Having selected radiation therapy, he was required to go out of town in order to obtain his treatments. Over a seven week period, Léopold and his wife would travel to the treatment centre over 500 kilometres away very early on a Monday morning and stay within the community until late Friday evening. His extensive radiation therapy required him to obtain treatments three times a week, for the seven-week duration. Léopold described this experience with fond memories:

Moi c'était un holiday quand j'étais là-bas. Ah oui! J'allais au casino, quand qu'ils me payaient je jouais, quand ça voulait pas me payer bin j'arrêtais. (Rire)
Ah pis j'avais des bons amis itou là-bas! (Rire)

When probed about these fond memories, Léopold's wife, who was present during the interview, attempted to rationalize his nonchalance by stating: "*Bin il était pas vraiment malade, ça le rendait pas vraiment malade. Pis si il avait été malade ça...*". Thus, in her view, Léopold enjoyed his treatment experience because he had been asymptomatic at the time of his diagnosis and experienced very few side effects from his treatment. Thus for him, having paid travel to another city where he was surrounded by friends was viewed as a vacation rather than a burden.

The presence or absence of pre-treatment symptoms was shown to have a great impact on participants' overall account of their prostate cancer experience. Without an ideal cancer therapy

for everyone, the process of selecting and receiving treatment was as varied as the men who participated in this study. Final treatment decisions were based on various personal and practical factors, and all men responded differently to their treatment.

4.4 Chapter Summary

Chapter 4 highlighted in participants' own words the feelings and challenges they experienced upon receipt of the news of their prostate cancer diagnosis. In addition, this chapter identified the various strategies and support systems these men utilized when attempting to obtain information in order to make important treatment decisions. The challenges they faced as a result of being members of a linguistic minority group seeking treatment for prostate cancer in Northeastern Ontario were also highlighted. However, the consequences of their final choice of treatment extended beyond these initial challenges to determinedly affected other aspects of their physical, social, psychological, and spiritual quality of life. In the following chapter a closer look will be taken at the strategies participants utilized to cope and adapt to the resulting consequences of their treatment choices.

CHAPTER 5:

PARTICIPANTS' POST-TREATMENT QUALITY OF LIFE

In the following chapter, we will delve into a deeper discussion of Francophone patients' post-treatment quality of life and highlight some of the strategies they utilized to overcome some of the access and service barriers they experienced. This chapter will also highlight how participants' sense of masculinity and sexuality interacted with their post-treatment relationships, how their community participation impacted their adaptation strategies, and finally, how their redefined self-value and assessment of the importance of altruism influenced their post-treatment lives.

5.1 French and English Health Services: Similar, But Not the Same

Geographically, all men represented within this study were from areas within Northeastern Ontario and as such, many of the barriers to entry into the health care system experienced were similar in nature. For example, veritable lack of specialists (e.g., urologists, radiologists, family medicine physicians) within these northern communities rendered it more difficult for all patients to obtain the necessary treatment for cancer-related illnesses. However, findings from this study have also highlighted certain inefficiencies in relation to the needs of the Francophone population. While most participants within this study spoke of their experiences fighting a battle against a potentially life-threatening disease, their accounts also pointed to an even greater battle as participants' struggled for their right to obtain quality health care in their own language. Some participants shared their stories of multiple extended trips to far away cities in order to obtain treatment in the French language; while others testified of their relentless challenges obtaining funding support from various provincial travel grant initiatives in order to access French services that were located outside of the regional health authority area in which they resided. Participants offered muted acknowledgement of the difficulties they endured in attempting to understand the plethora of medical information they were required to absorb and then act upon, within a language they were not familiar with. While the intimate nature of prostate cancer symptomology could be uncomfortable for all prostate cancer patients, participants in this study who could not speak the dominant language with enough proficiency to make significant medical decisions were often obligated to seek assistance from their adult

children, friends, or hospital personnel in order to convey necessary and often sensitive information to their medical team. In addition, participants also spoke of the informal manners in which they sought to understand their diagnosis of prostate cancer (e.g. speaking to their friends who had previous experience with the disease, asking adult children for assistance in researching the internet for treatment options), French sociologist Marie Ménoret (1999, 2007) speaks of the impact of the diagnostic meeting whereby the physician introduces the person into their new status as “patient” and recognizes this formal interaction is founded on an inherent contract between both parties which is based on a principle of uncertainty. Ménoret stresses that although this medical uncertainty is experienced by both parties, the type and extend of this uncertainty varies based on the level of trust and confidence each party possesses (Ménoret, 1999; Ménoret, 2007).

The ability to trust one’s medical team necessitates a precognition of understanding of both the disease itself and the recommended course of treatment. For most participants, their initial diagnosis of prostate cancer was unexpected and even for those men who had previous symptoms; their disbelief upon hearing that they had cancer was difficult to process. However, participants’ within this study appeared to experience an additional burden during this phase of their illness experience specifically related to their inability to understand much of the information being provided to them during meetings with their specialists. This language discordance extended beyond the misunderstandings that can occur when attempting to understand information being presented within a specialized medical terminology; for them, this language disparity occurred at a fundamental level of understanding the actual language in which these specialized medical terms and processes were being presented. As previously mentioned, many of these men were forced to seek out additional information and assistance from other members of their personal and social networks in order to make sense of the medical information they were provided in a language and subject matter most of them were unfamiliar with.

In an attempt to better understand the impact of treatment on men’s quality of life, I also posed questions related to the physical, psychological and social consequences of their treatment decisions. What was most interesting within my findings was the intense vulnerability men experienced in the face of a possible loss of their quality of life; which they mostly defined in terms of their physical and sexual functioning. In fact, the testimonies provided within this study

highlight a paradox that exists between participants' need to maintain a sense of control over their bodies while being unable to take ownership of the decisions that could affect their sexual functioning. In other words, while men are often viewed as being uninterested in their health and bodies, participant accounts supported evidence of the existence of an internal battle men experienced between their need to maintain a certain aloofness (or masculine indifference) in relation to their health and their need to act swiftly and decisively in the wake of their diagnosis. This paradox was often presented within their accounts of needing to "remove the cancer" or "cut it out" while simultaneously admitting to their own inability to make the final treatment decisions when these decisions could compromise their virility. When speaking of men's decisional difference, I am acknowledging my belief that they do so as a tactical mechanism to preserve their own sense of masculinity by shifting the potential sexual consequences of their treatment decisions away from their own self and onto their partner as a means of jointly holding responsibility for any loss of sexual functioning. In allowing their wives to play active roles in the decision-making process, these men are affording themselves a certain degree of separation from their own bodies by compelling their partners to become accountable for the results of these decisions. From this perspective, men are therefore able to transcend beyond the social implications of changes to their masculine status since they are in essence, experiencing these consequences in order to comply with the treatment decisions made by their spouses. A number of studies have identified information needs among men diagnosed with prostate cancer and recognizes the fact that prostate cancer treatment decision-making requires complex trade-offs among therapy outcomes, and sexual function is a central consideration for most men (Droupy, Al Said, Lechevallier, Colson, & Giuliano, 2013; Harden et al., 2013; Hoyt, Stanton, Irwin, & Thomas, 2013; Klaeson, Sandell, & Bertero, 2013).

Research conducted by Knight (2009) and colleagues found evidence that concerns about sexuality were not proportionate with the associated risk for sexual problems with various prostate cancer treatments and highlighted the fact that most prostate cancer patients and spouses in their study acknowledged unmet needs for information about sexuality in making prostate cancer treatment decisions (Knight & Latini, 2009). Compounding this issue is the understanding that sexuality is socially constructed and for many men, it is an extremely personal and nuanced experience that consists of a variety of constructs including, but not

limited to, beliefs, attitudes, preferences, desires, behaviours, functions and relationships. While Knight's (2009) study suggested that sexual function was less important among men diagnosed with prostate cancer than concerns about survival, participants within this study struggled with making treatment decisions that were likely to impact their sexuality and masculine identities. For many, the decision to differ to their spouse in essence released them from any guilt or social stigma related to the sexual consequences of their selected treatment. As such, participants' accounts were strongly related to the important social and cultural component of their decision-making process in that they tended to recount their experiences in relation to their broader community and personal relationships. For them, their post-treatment realities were mainly psychosocial in nature (e.g. relationships with friends and family; their ongoing contributions within their community; their ability to maintain a strong work ethic) and their accounts of the difficulties they encountered during their illness experience largely focused on the communication issues (in both providing and interpreting information) within the current model of health care. Thus, recognizing a diagnosis of prostate cancer as a subjective experience, there is value in understanding men's challenges with the disease and its implications within a culturally constructed context. For example, a recent grounded theory study conducted by Wenger's (2013) offered a broader conceptualization of the dynamics that exist in men's cancer experiences and highlighted patterns of fear, uncertainty and feelings of isolation which were saturated with societal expectations (Wenger, 2013). For participants within this present study, similar social, relational and cultural imperatives dominated their accounts of their experiences with the disease and the implications of their decisions on their post-treatment quality of life.

5.2 Living with the Physical Side Effects of Treatment

As mentioned earlier, there are several treatment modalities available in the fight against prostate cancer (Chung & Brock, 2013). Current medical literature indicates that surgery for prostate cancer typically results in the possibility of urinary or sexual dysfunction and pain or fatigue following the procedure (Kimura et al., 2013; Namiki et al., 2012). Radiation therapies can also result in physical maladies such as the inflammation of the back passage (proctitis), erection problems (impotence), bowel and bladder incontinence, and fatigue (Fransson, 2008; Namiki et al., 2006). Hormone deprivation therapies are often associated with physical side effects such as hot flashes and sweating, breast growth and tenderness, and loss of libido. Side

effects from long-term hormonal therapies can also include weight gain, memory problems, mood swings and depression as well as bone thinning (osteoporosis) (Kyrдалen, Dahl, Hernes, Cvancarova, & Fossa, 2010; Mols et al., 2009; Sevilla et al., 2012). The following chapter is broken down into categories based upon the physical side effect noted. Readers are reminded that most participants in this study received one or more of the above treatment modalities, and as such, may have experienced several side effects throughout the course of their illness experience.

5.2.1 Incontinence

The inability to control the flow of urine was a commonly reported side effect of surgery. For Théo, experiencing incontinence was minimized by the potential consequences of not seeking treatment. He shared, “*Quand j’ai été opéré là, ya rien qui marche. C’est ça qui a été le plus dur à... à accepter là (...) il faut que tu te concentres à ça. T’sais, c’est ça au bedon... si tu te fais pas soigner tu... tu meurs*”. Cédric Jr., who also underwent a radical prostatectomy, shared his experience with incontinence following his surgery:

Là j’allais à toilette pis m’en va la faire fonctionner, mais là ça... ça fait du bien, ça coule, mais... Mais ça dégoutte tout le temps un peu. Quand je travaille, m’a dire j’essaye de lever de quoi là bin... c’est pire eh. Il m’a dit de pas lever plus que 10 livres. Moué j’étais assez travaillant... J’ai toujours été travaillant, pis... [une fois] j’ai donné un coup sec j’sais bin eh... Oh! J’ai senti pincer, pincer là! C’est là que ça l’a commencé. À me pincer... ouais. J’ai toffé que ça une secousse, mais... des fois je forçais un peu trop eh, pis... Ça coulait plus dans ce temps-là là. T’sais... c’était pas assez... sévère pour moué eh... je me laissais aller pis... si il avait de quoi à faire il le faisait pis... je regrettais après pis (Rire)... C’est plus fort que moué eh. Quand t’aimes à travailler.

Incontinence was also a post-surgery issue for Félix, however, he rationalized it as a “small price to pay” to rid himself of his prostate cancer, “*La première complication que j’ai eu, c’est que j’avais pas d’retention d’urine. Alors euh, ça sa c’est corriger légèrement. C’est pas régler. Ça m’dérange pas si l’cancer est pas là. Ça sa m’dérange pas.*” The above accounts pointed to the important realization that these participants viewed incontinence as a minimal burden since they understood it as the cost they had to pay in order to save their lives. In this

view, cancer was seen as the enemy; one that could kill you. And while changes to their ways of living (or ways of working as was the case with Cédric Jr.) may have been difficult to process, these participants were able to rationalize these issues in light of a more critical alternative.

Another participant, Éliam, was also left incontinent after his surgery. He explained that wearing diapers was now a part of his daily routine. When probed on how he handled this new reality, he shared the following story:

Asteure que... j'ai pas peur d'en parler que... même mon problème que j'ai là, j'ai... t'sais je le cache pas j'ai... c'est comme je dis au monde, je fais des jokes là-dessus t'sais? C'est comme une madame l'autre fois, je va au magasin, elle dit, elle me voit sortir avec des boites de couches, elle dit " Vous allez garder des bébés? " Elle a partie à rire. J'ai dit " Non" j'ai dit " Le bébé est icitte (Rire). Je porte des couches de bébés euh...".

Suffering from a chronic illness such as prostate cancer can cause great humiliation for men, especially when these cancer-related experiences are inconsistent with dominant forms of socially constructed masculinity (Oliffe, 2005; Oliffe, Ogrodniczuk, Bottorff, Hislop, & Halpin, 2009; Oliffe & Thorne, 2007) which are often characterized by expectations of strong independence and control, self-reliance, power and stoicism (Courtenay, 2000). Éliam's use of humour was one strategy he employed in order to cope with the humiliation he felt because of the physical effects of his treatment decision. In fact, the vulnerability he experienced over the loss of control of his bodily functions was further exacerbated by his wife's inability to come to terms with his incontinence. He shared:

Ma femme, ça l'a dérangeait un petit peu au début, mais pas tellement. C'est après l'opération, vu que j'ai resté de même là, que ça l'a dérangé plus. Euh, elle trouve ça, elle trouve pas ça facile dans le moment, t'sais de me voir à couche de même là t'sais. Ça fait plus de la rage quand qu'on dit... t'sais, changements et puis tout ça. Pis ça... c'est là qui est le plus dure dans le moment pour nous autres.

Unfortunately, the challenges both Éliam and his wife were experiencing as a couple were not unique. In fact, an integrative review on the impact of urinary incontinence on the lives

of wives of men with incontinence conducted by Bicalho and Lopes (2012) demonstrated a significant link between male incontinence and spousal psychological distress; largely due to the changes it caused in the couple's sex life and the limitations that being incontinent posed on their social life (Bicalho & Lopes, 2012). While Éliam may have been able to use humour to avoid public humiliation, he later shared that the impact of his incontinence on his wife and on his marriage were issues that very few were privy to. While previous studies have shown how men react to various treatment effects (Hart, Latini, Cowan, Carroll, & CaPSURE Investigators, 2008; Hong, Hu, Paciorek, Knight, & Carroll, 2010), studies are now emerging that focus on the specific responses of spouses to a diagnosis of and treatment for, prostate cancer. For example, an integrative literature review conducted by Resendes (2006) highlighted various sources of spousal distress such as the lack of information (pre and post treatment), the fear of the unknown, the fear of what the future will hold (both for the husband and for the couple), and treatment-related concerns (Resendes & McCorkle, 2006).

The consequences of spousal distress varied among participants. While some, like Éliam, shared muted acknowledgements of the changes in their relationships, others shared more serious accounts of how the physical consequences of treatment for their disease affected their personal relationships. For example, with difficulty, Éllie Jr. spoke of his post-treatment side effects and shared his belief that it was, in fact, his incontinence that was the primary cause of his separation from his wife: In a strained voice, he shared:

Pour moi l'opération a été très très difficile. Pour commencer les quelques premiers mois toute c'est arrangé j'ai, pis eh, à moment donner là j'ai eu des, des, des problèmes avec eh l'incontinence pis eh, (...) après trois opérations là [pour tenter de réparer la vessie], c'était l'in, l'incontinence à 100% vu c'était vraiment inconfortable. Pas d' qualité de vie as t'heure là... Ben non, écoute un peu là, y'a, veut dire eh, la vie sexuelle. Pouf! C'est sur le diable et puis eh, pis tu dis même, eh, avoir la virilité si t'est incontinent c'est une condition un peu eh gênante eh. T'a un homme seule avec une femme et pis ta possiblement des femmes qui comprendraient l problème mais eh, y, ça serait, ça serait eux autres à trouver eh.

He later shared why he thought his wife left him:

Possiblement, possiblement la vie eh conjugal eh fait que ma femme... Moi, j'étais plus informé qu'elle sur le cancer d'la prostate, dans l'opération pis avant les traitements et puis elle a tout le temps présumé que j'en avait pas dit assez. Mais qu'en on voulait en parler, souvent elle voulait même pas écouter parce que a dit si ça t'occupe pas toi... pourquoi ça m'occuperait moi pis eh. C'était après ça pour elle le choc était plus grand... Faque ça (Dégage sa gorge) Et on, on n'aurait séparer trois ans ensemble pareil après l', l'opération... Jusque a la séparation bien entendu. (...) Mais comme on dit, chaque jour suffit ça peine fait qu'on prend ça comme ça l'arrive pis... (Dégage sa gorge). C'est un peu émouvant parler tout ça là mais... ça ramène des souvenirs. Naturellement on, on s'habitue aux conditions existantes... parce que notre condition eh, notre condition eh, on dirait notre condition par exemple jamais ne nous contente. La pire c'est toujours eh celle-là qui existe présentement là. T' sais qu'on veut Mais, sur l'ensemble, on s'habitue au condition et pis on vit avec. Pis eh, c'est un jour à la fois.

Had he been aware of these outcomes at the time of his treatment decision, Éllie Jr. acknowledged that he would have made a different choice, *“Avoir sûre bien entendu que l'opération aurait été telle qu'elle a été, pis les complications etc.étéra, etc.étéra, peut être que j'aurais avoir, avoir eu le choix, avoir su. J'aurais opté pour la radiation mais pas l'opération”*. The above accounts undoubtedly highlight the potential quality of life impact on the relationships of prostate cancer patients and their spouses.

5.2.2 Impotence & Emasculation: The End of Sexuality and Enjoyment

Difficulty obtaining an erection (impotence) is a frequently cited consequence of treatment for prostate cancer. This common sexual side effect was described by many respondents as the primary measure in which to assess their post-treatment quality of life. In fact, when initially questioned on changes to their quality of life, several respondents solely referenced changes that had occurred in their sexual capabilities. Such was the case for Isodore, who when asked about changes to his quality of life shared:

Bin genre, le sexe c'est plus comme c'était. Ça l'a... j'ai pas d'érection, tu vois... J'ai pas été capable d'avoir des euh... des érections pour la pénétration, mais il

[son médecin] dit “ Dit à ta femme qu’elle te stimule pis tu vas être correct”. Pis j’ai des orgasmes sans érections. C’est ça, c’est ça que j’ai.

While the challenges for prostate cancer survivors are not limited to the management of physical and sexual quality of life issues, sexual functioning remains an important issue for most men, many who continue to be interested in sex after treatment for their prostate cancer (Chung & Brock, 2013). In fact, it has been shown that the impact of sexual dysfunction is greater than the impact of urinary incontinence (Meyer, Gillat, Lockyer, & MacDonagh, 2003). Current research also alludes to the impact of sexual dysfunction on the lives of spouses and intimate partners (Badger et al., 2011; Harden et al., 2013; Rivers et al., 2011; Sterba et al., 2011). For example, when probed on how he and his wife handled his post-treatment impotence, Isodore revealed:

C’est juste que... ça change ta vie d’amour, bin de l’amour ça change. Ouais... ça me dérange pas disons là t’sais... je pense pas à ça trop. Non, pas... c’est pas de quoi qui me met... t’sais qui me met down disons, OK avoir eu le cancer... mais pas ça (...) Mais... ma femme est très understanding là... pis a... elle me supporte beaucoup pis elle... elle a pas l’air à déranger... sa vie là elle.

Like Isodore, several participants indicated that their relationship dynamic with their spouse was central to their evaluation of their post-treatment quality of life. More specifically, the level of support and the nature of the relationship they had with their wives were shown to be of critical importance in their determination of impotence as being either a major concern or a minor inconvenience of their treatment protocol. For Stéphane, aged 67 at the time of the interview, changes to his sexuality were not viewed as a major issue but rather as a normal part of aging that necessarily forced him and his wife to redefine parts of their relationship. When asked about his post-treatment quality of life, he shared that very little had changed:

Non, peut-être sexualité...c’est pas comme avant. C’est pu, c’est pas comme avant, mais c’est pas rien qui est un problème...Mais, quand on dit, pour moi c’est pas un problème, parce qu’il en a qu’ils sont plus jeunes que moi, ils n’ont pas passé au travers, puis ils ont des problèmes sexuels. Ça fait que, c’est peut-être normal qu’à un moment donné à un certain âge on diminue itou. K? J’suis certains que dans la vie uh... ça meurt pas tout en même temps cette affaire-là

là. Non, pour nous autres ça pas été, ça pas été un problème. Disons qu'on manque ça, personnellement là. On le manque, asteure j'ai appris que c'est plus un p'tit hug, t'sais des choses de même, on découvre d'autres choses (...) On aime d'une autre manière. K? Parce que sexuel c'est sexuel, mais on peut aimer quelqu'un sans avoir du sexe. T'sais comme, ça c'est des choses quand que t'es jeune, on pense pas, mais moué personnellement, je parle pour moi qu'on, oui on... mais on réalise qui a beaucoup d'autres choses au côté. On réalise, chez pas moué, il fait beau à matin, on est chanceux, on est béni, on a du camping, on fait du camping, on... ça pas changé notre, eh?

While there is evidence that regular (consensual) sexual expression can contribute to physical and psychological well-being, and may reduce physical and mental health problems associated with aging (Burgess, 2004), Stéphane's account highlights a redefinition of quality of life; one where the conceptualization of intimacy and connection are redefined at the exclusion of physical sexual activity. In several participant accounts within this study, physical quality of life omitted the notion of sexuality. For example, Quentin expressed his acceptance of his non-sexual post-surgery reality when he shared:

Bin, pas bin bin. Bin le sexe, une question de sexe je cré bin t'sais... c'est fini. Pis ma femme, moué pis ma femme on est d'accord, bin c'est elle qui veut pas que je prenne des... des pilules comme... Ouin. Ouin, non, c'est correct avec ça. Non, moué j'suis correct avec ça moué. Je l'ai accepté, pis je golf pareil, pis je travaille pis... bin je travaille, je chauffe des autobus scolaires, j'suis à la retraite eh. Pis je m'occupe des autobus le matin pis le soir pis... pis là bin des fois dans l'hiver on prend une couple de semaines pis on va dans les pays chauds pis....'

Another participant, Déjean Jr., also expressed a similar rationalization when he spoke of his current quality of life:

Le sex life... c'est fini là. Mais, après... après il a d'autres choses. Nous, on fait des voyages, on fait toutes sortes d'affaires, on a beaux restaurants! On fait toutes sortes d'affaires, y a pas ainque ça dans vie! On va dire comme qu'on dit, quand qu'on était jeune on y a donné la claque, pis là asteur (Rire)... on laisse ça aux autres.

However, it should be noted that not all participants were as adaptive to the physical consequences of their treatment for prostate cancer; especially in reference to the challenges they posed to their traditional scripts of masculinity (e.g. being unemotional, being self-reliant, being powerful, being independent, defining one's worth in terms of sexual potency) (Helgeson & Lepore, 2004). According to Cornell (1987), masculinity can be defined as a social construction about what it means to be a man in a certain time and place (Cornell, 1987). As such, various definitions of what it means to be a man should be recognized as both historically and culturally driven (Tannenbaum & Frank, 2011; Wall & Kristjanson, 2005). Currently in North America, roughly a half million men are on androgen deprivation therapy and are essentially chemically castrated (Wassersug, 2009). Within this study, one participant account particularly highlighted the specific challenges associated with the side effects of hormonal treatment. Onézime explained:

J'ai juste, j'ai perdu beaucoup de forces physiques là, à cause des traitements. C'est les traitements qui sont durs. Les hormones de femme sur un homme là, ça fait dur. C'est dur. Le pire c'est l'atrophie des organes sexuels. Ça, ça l'a été plus difficile à accepter ça . (...) Pis ça s'est remplacé, j'ai pas eu, ça pas fait mal longtemps (Rire). Parce que t'sais perdre sa virilité, c'est pas facile, c'est pas facile, t'sais imagine un peu là perdre ta féminité. C'est pas facile ça là là.

Coping with his penile atrophy was a difficult process for Onézime. However, his account also pointed to the emasculating reality of androgen deprivation therapy:

J'ai passé assez bien à travers à cause de ça t'sais, cette question-là là, t'sais où ce qu'elle est ma valeur humaine? Pis c'est pas vraie qu'elle est dans mon, tout dans mon érection. T'sais, c'est parti, ma libido c'est ainqu'un souvenir (Rire). Pis c'est correct, t'sais, comme des personnes qui étaient là avec moi en traitement, si on a pas profité dans le temps que c'était le temps là, bin il est trop tard pis c'est tant pis (Rire). Pis j'ai aimé ça. Mais, ça m'a tellement amené à être, à penser positif que ça l'a pas été long, il a une question qui s'est amené à mon esprit, " Ma valeur humaine es tu toute dans la longueur pis la raideur de mon érection, ou bedon est pas ailleurs? " (Rire)

Wassersug (2009) believed in a lack of impetus within the medical community to encourage patients to accept, let alone embrace, the reality of emasculation of androgen deprivation therapies. More specifically, he claimed that many of the resources available to patients actually minimize the feminizing effects of treatment. However, in this particular case, Onézime was able to process his new reality by reconceptualizing his existential beliefs of manhood and masculinity. More specifically, recognizing that his “worth as a human” extended beyond “the length of his erection” helped him move beyond his preconceived notions of manhood and redefine his sense of worth as a man.

Other participants were also able to redefine their manhood. For Zachérie, a Francophone participant who chose to conduct his interview in a mix of both the French and English languages, masculinity was attached to his ability to continue riding his motorcycle. In his words, he stated, *“It was weird because they put me under, they do a procedure and I come to and... the first question that I have was “When can I ride my bike?”* Other participants shared how they believed their physicians downplayed the possible negative side effects of a prostatectomy on a man’s sexual health. In referring to his post-surgery issues, Félix said:

Naturellement, l’autre problème qu’y’est relié à ça, c’est au niveau euh, relations, euh, sexuelles. Naturellement, et ça c’est le, d’après c’que j’ai lu par après, les spécialistes minimises cet effet là. Y disent que le pourcentage de personnes qui vont être affectés est minime. Puis d’après c’que j’ai entendu par après de d’autres personnes, c’est loin d’être minime.

Another participant, René also echoed a belief that health providers minimize the potential sexual consequences when he stated that *“les médecins disent pas la vérité, parce qu’ils la savent pas la vérité... ils la savent tout simplement pas”*. René’s wife, who was also present during the interview, held a different opinion as to why physicians made light of the potential sexual consequences of having surgery for prostate cancer. Referring to the “Between Us: Living with Prostate Cancer in Canada” magazine, she stated:

Bon. On lit là-dedans (la revue “ Entre-Nous ”), pis il en a beaucoup d’hommes qui le disent là-dedans, que t’sais, à chaque mois il a tout le temps un article, un homme qui rencontre son aventure de cancer de la prostate. Pis il en a des hommes qui le disent qui perd la virilité, mais les médecins ils ne te le diront

jamais et moué je pense que c'est parce qu'ils ont peur que leurs patients prennent une mauvaise décision en mettant ça en ligne de compte.

As a couple, René and his wife found various ways to support each other during their cancer experience. As mentioned in the previous chapter, René's wife was the final treatment decision maker when René's fear of impotence left him unable to act. When asked how his treatment had affected his quality of life, he stated, "*Sur la qualité de vie... ça pas changé grands choses à part... à part du sexe. Disons que ça l'a changé peut-être... une heure de vie... un heure de vie par semaine. (Rire) À notre âge, c'était une heure, une heure et demi par semaine, ça changé (Rire).*" Later, using an analogy of the impotent men kept as slaves to care for the wives of the Egyptian pharaoh, he shared:

Mon drive là... il baisse. Il baisse, il baisse, il baisse, il baisse. T'sais que... un homme là... à quand qu'il est normal là, il pense au sexe à peu près à toutes les vingt minutes... quinze, vingt minutes il pense au sexe... d'une manière ou d'un autre, pis ça le fait réagir, pis ça le fait... t'sais. Bin là là, moué des fois je pense au sexe à tous les six mois (Rire). On y pense plus. C'est... c'est toute parti ça. Ça c'est, ça c'est après quelques années là, c'est à peu près 4, 5 ans, 5, 6 ans après là. Comme moué de ce temps icitte là, je... je suis plus attiré par les poissons là. (Rire). Je suis comme un eunuch, Ouin... déjà là, quand qu'ils voulaient avoir... dans les pharaons, les... les gardiens de leurs femmes, ils les castraient là, pis ils s'occupaient plus, ils se cassaient pas la tête, c'est gars-là ils étaient, ils étaient parfait pour aider à leurs femmes pis tout ça, mais... ils pensaient pas à rien d'autre choses. Fait qu'on est, on est... c'est de même qu'on est rendu.

Through the reconceptualization of his sexual identity as being one of an "eunuch", René found a way to redefine his current state and has moved on to what he described as a fulfilling life. Although the labelling of himself in this manner may appear self-deprecating, it has in fact empowered him by allowing him an alternative to mourning his former manhood. However, René's physical changes were also experienced by his wife, who shared how the smell of his body had changed. For her, this was an unexpected outcome of surgery; one that she believed posed an even greater challenge to their continued intimacy. Questioning her own assumptions, she shared:

Ça se peu tu que mon mari à cause qu'il a pu... qu'il fabrique pu autant de testostérone, sa sueur..." un homme... tu sens sa sueur t'sais, quand qu'on a des rapports, il avait pu de senteur lui, il avait pu... sa sueur, je la sentais pu comme avant. (Pause) Parce que, il en avait moins de testostérone. Pis ça j'veux dire... c'est quelque chose qui t'attire là avec ton mari, t'sais, ça fait parti de... de ta vie sexuelle. Pis ça, j'suis pas capable de parler... j'ai d'la misère de parler de ça avec d'autres femmes, parce qu'il a des femmes qui s'aperçoivent pas de ça. Mais moi j'm'en apercevais là.

Speaking of her husband's current sexual status, René's wife then commented on how a couple's previous relationship dynamic would play an important role in their post-treatment realities and the new ways they could negotiate their sexual relationship. She explained:

Les femmes, les femmes qui aimaient pas le sexe. Eux autres ils sont, ils sont soulagés. Sont... c'est pas écrit dans leur visage, on le sait pas là, t'sais. Mais, c'est quelque chose que... c'est parce que les hommes s'inquiètent après ça. Bin, t'sais... ma femme elle aura pu de sexe là, pu de sexe c'est... c'est bin certain que tu peux continuer avec la tendresse, la tendresse là, t'sais. Mais, il faut que tu trouves d'autres moyens.

Another participant, Félix shared an account that gave insight into the fact that one's spouse and their medical conditions can also play a role in how the sexual consequences of prostate cancer treatment are experienced. He shared:

Ben, euh, j'pense que pour elle aussi le principal c'est que l'cancer ne soit plus là. Les autres aspects devenaient secondaires. Puis euh, j'ai vue des gens par exemple, où disons l'aspect relation avait une très grande importance pour l'épouse. J'ai vu un cas au moins où y'a une séparation, elle est partie, parce que, elle n'était plus satisfaite. Maintenant, mon épouse, mon épouse a euh, a souffert passablement de dépression. Et les médicaments qu'elle doit prendre pour combattre ça vont par l'effet même diminuer la libido. Donc l'effet dans ce cas là est beaucoup moins important. Ce n'est pas un besoin, disons de, sur une base régulière comme ça peut l'être, euh, avant.

Within the realm of sexuality, a variety of side effects were described by the men who participated in this study. While several men spoke about the loss or change in sexual desire, Iréné Jr. offered a contradictory account of his post-surgical sexual drive. He stated:

Bin... les docteurs ils vont dire... le docteur icitte dit aux femmes que... là t'as ou d'érection eh... c'est vrai, t'as pu d'érection... mais! T'as encore... dans mon cas, t'as encore le sentiment encore... t'es encore... t'es encore... tu viens encore exciter... soit de... l'estomac... ou partiellement, un p'tit peu... comme on dit... " Ohhh... oops " t'sais. Mais... euh... une chose que les docteurs... encore... m'a utilisé le mot " réjouit " eh, climax... réjouit. Je réjouis pareille. Tu savais pas ça eh. Tu réjouit pareil. Dans mon cas! Ouin... j'aime encore le sexe pis tout ça... j'me sens excité, tout... oui. Euh... pis... Euh... je réjouis pareille. Euh... pis quand que je réjouis... euh... j'éjacule pas. Là j'ai pu de prostate là... c'est l'urine qui sort... c'est l'urine qui sort. Mais je... pour réjouir comme avant, non. Euh... c'est impossible. Mais encore... la friction, selon la chaleur... blah, blah, blah... euh... je réjouis... pareille.

Ejaculatory function is often an underreported aspect of male sexuality in men treated for prostate cancer (Huyghe et al., 2009; Walz et al., 2007). However, this underrepresentation should not minimize the symptomology since for many men, like Iréné Jr., it can be a very bothersome side effect.

5.3 The Psychosocial Side Effects of Treatment for Prostate Cancer

In addition to the physical side effects of prostate cancer and its treatment, participants in this study spoke of side effects that were psychosocial in nature. Some of these appeared to be directly linked to the various physical symptoms they were experiencing (illustrative of Onézime's experience accounted for in the previous section), while others were not. The psychological, emotional and/or social side effects highlighted within this section are primarily related to participants' experiences reported having occurred at later stages of their illness experience.

5.3.1 Fear of Abandonment

Fear and guilt were common themes cited by participants in this study. For some, it was the fear of embarrassment that led them to becoming withdrawn from others. In reference to other men he knew who had completely isolated themselves after their treatment for prostate cancer, Déjean Jr. exclaimed:

C'est surtout... le cancer de la prostate, il en ont qui vont dire ... Bin eille, ils veulent pas le dire, ils sont gênés de le dire! Parce qu'ils veulent pas le dire, parce que c'est certain qu'il a des conséquences. Le cancer c'est pas un sujet tabou. N'en parler! C'est là que tu n'en parles, c'est là que t'as des petits trucs, des petits trucs de un, pis des petits trucs de l'autre.

Another participant, Moïse, openly spoke of his post-treatment experience being akin to depression, albeit short-term. He told of the immense fear and guilt he experienced because of the physical side effects of his surgery (e.g., incontinence, impotence and at times, severe pain) and their impact on his relationship with his wife. He explained:

Il a des fois quand elle reviens sur certaines choses... (Pause) J'ai dit que c'est pas de ma faute... (Petite voix) si je suis emmanché de même. Comprends-tu là? C'est pas de ma faute si j'suis de même. (Pause) " Ah mais t'sais..." Pis mes trois enfants ils me disent " Dad, dad, part pas" pis tout ça. (En pleurant) Pis des fois ça fait mal icitte. T'sais, t'sais... ça fait mal icitte. Ça fait, qu'est-ce que tu veux? Pis c'est ça... c'est ça que c'est. (Pause) Il a des, des il y a des escousses, t'sais, c'est numéro 1, pis il a des escousses que ça revient... Mais t'sais on peut pas... t'sais. C'est pas de ma faute! Qu'est - ce que c'est que tu veux que je fasse? T'sais à notre âge là... elle dit " Il en a que ça va bien" " Ah oui, oui, oui, oui" T'sais ça va bien, pis que... t'sais pis que, ils ont des relations de sexuels, pis comment est-ce que c'est pis qu'on est passé 60 ans, pis quessé c'est que tu veux que je fasse? T'sais, c'est pas de ma faute. T'sais-tu revire pas le couteau... t'sais, le couteau dans plaie, tu comprends-tu là? Fait, quessé tu veux faire?

Although Moïse acknowledged the immense strain his disease had on his relationship with his wife, he was quick to acknowledge that she could have left him as he had witnessed other spouses do. He continued:

Mais elle été bonne, elle a été bonne. T'sais, j'peux pas dire là qu'elle a pas... parce qu'il en a... moué j'en ai... j'en ai de mes amis moué, (...), que je connais bien là... pis que la femme, la femme est partie. C'est pas drôle. C'est pas drôle là quand tu t'arrêtes pis que... pis tu penses à ça là, t'sais. Pis moué bin ça m'a pas arrivé ça. Pis c'est pas ça... en tout cas. Ça fait que c'est ça que c'est.

This inherent fear of spousal abandonment was echoed by René who, in the presence of his wife, shared:

C'est pas, c'est pas un... c'est pas un péché ça là là, c'est... c'est ça, c'est ça c'est la vie. Mais j'ai encore la vie! C'est ça qu'elle (sa femme) me disait. J'suis t'encore debout. Fait que... t'sais... des fois on-dit " La vie est pas si rose " mais, au moins on l'a et au moins elle est encore icitte avec moi! Le... le gars qui est en chaise roulante il est quadraplégique, le... il a encore la vie, mais a pas tout, il a pas tout les... les bénéfices de la vie encore non plus. Moué, à part du sexe, j'ai tous les bénéfices de la vie, je peux aller à pêche, je peux faire n'importe quoi, je travaille encore.

The fear of spousal abandonment, as described above, was an underlying theme in many participants' accounts of living with the consequences of treatment for prostate cancer. As alluded to in previous sections of this thesis, the effects of treatment for this disease go beyond the physical changes men experience and greatly influenced their psychological well-being and their personal relationships. While several participants spoke of the role played by spouses, other family members and friends in helping them cope with the psychological effects of the disease, Éllie Jr., offered a different account of his experience. He explained:

À vrai dire c'étais, j'avais pas l'impression d'avoir besoin d' support. J'avais l'impression que la médecine était pour régler le problème et puis c'était juste question de temps. Et, dans l'temps que j'éte eh au, au centre eh, voyons, du cancer (...). Au centre du cancer, y avait pour ceux là qu'avait besoin d'aide eh psychologique si on veut dire mais, j'ai jamais penser d'aller dans les salles et puis, écouter même parce que j'ressentais pas le besoin moi même eh, ça va s'arranger tout simplement parce qu'en beaucoup qu'y on l'cancer dans le passer pis s'on vivant aujourd'hui pis. J'avais des exemples des personnes que

j'connaissais qui avait eu cancer et pis qui fonctionnait. Et puis eh, si eu autre on guérit eh, j'avais suivre le même trajet moi aussi et puis tout va rentrer à l'ordre.

Éllie Jr.'s account demonstrated a line of reasoning where he was able to transpose his current position as a cancer patient with that of those men whom he had previously known to have experienced the same diagnosis. For him, their success with treatment offered him tangible proof that he too could be cured of this disease. By following the same treatment path as those cancer survivors, he felt confident that he would experience a similar fate. However, not all participants shared Éllie Jr.'s optimism. In fact, even those who found themselves in remission were often still plagued with the fear that one day their cancer would return.

5.3.2 Fear of Recurrence

Several participants also commented on the perceived threat of recurrence of their prostate cancer. For some men, it was an ever-present concern that lingered in the back of their minds, while others managed to distract themselves from its presence until the time of their annual check-ups. For example, when asked how often he thought of his prostate cancer, Éliam, who was treated for his disease eight years prior to our interview, shared:

Ah j'y pense toujours parce que j'ai... t'sais... comme je disais taleur là, le cancer, ça reste que c'est toujours le cancer eih. Tu, tu penses toujours que... un jour que... ça va revenir t'sais. Pis c'est comme qu'ils disent... quand c'est un cancer qui tombe dain os, euh... tu sais pas ça ordinairement tu vas le savoir à dernière minute.

Doménic, having already experienced one incidence of recurrence since being diagnosed five years prior, also acknowledged:

[J'y pense] toujours. Comme de raison, le médecin y'a dit que ... ça veut pas dire que c'est ça qui va m'amener, ça peut être le cœur. Ben, tu y penses tout l'temps que ça peut revenir, oui. Surtout que ça là déjà revenue. J'ai tout l'temps cette inquiétude là. Définitivement.

Zachérie, who was diagnosed and received brachytherapy 48 months prior to our interview, also acknowledged that the fear of recurrence is a constant reality for him. He shared:

I still think about cancer, yeah. Much more now. Uh... well, I'll give you an example, uh... A few days ago, I was uh... went to the washroom in the morning, OK, and there was blood, right? So...red flag... internet, right? Uh... bright red blood uh... colon cancer, or whatever right? Oh... right away you're thinking "Uh oh! It's back... something's back" right?

Zachérie also conceded that the increase in his anxiety levels was most often linked to the timing of his semi-annual check-ups. When probed as to why he thought this was, he explained:

Because... well... they give you... they send me, no... they send me forms in the mail, and they'll say like, you know you got to be there on this date, one week prior to, or whatever... go to the hospital, get blood work done, right. Well, when they check your PSA, and that's... that's when the anxiety starts. I leave here, you go there, you get the blood work done, you're thinking "Blood work... pff, a piece of cake" they just... whatever... and then you're thinking "OK, now I got to go back, I got to go back and see him." And, it's funny because when you go there, you register and then you go to the other side, the other side... somebody comes and gets you, weigh ya, they weigh ya and then they have you fill out a questionnaire, right? And in the questionnaire, one of the questions is "What's your... anxiety level?" Right now, and I'd say "OK well, on a scale to 1 to 10 I'd be on a 5 to 6 range, because you don't know... I mean, you might go in there and you'll say... you know what... and you always think... well I guess the worse, right? So you're thinking "What if he tells you that your PSA has shot way up there?" What do we do from now? Like you know, because I know you told me that... if this Brachytherapy didn't work... we're going... right? So I'm thinking "Oh, shit!"

Another participant, Félix, mirrored Zachérie's account when he was asked if he ever thought about his prostate cancer and acknowledged that he only thinks about it when he is waiting for the results of his annual prostate specific antigen test:

C'est une drôle de, la question est bonne. Si j'y pense à la prostate, euh ... Au départ j'avais les tests de PSA régulièrement, là j'essaye d'y aller une fois par année. Et le seul, la seule occasion où j'ai des craintes là, c'est après qu'on a passé l'test. (...) Tout d'un coup ça serait revenu. Mais, en temps normal, non. Non.

Similarly, René admitted that even though it has been over 12 years since his original diagnosis of prostate cancer, he cannot last more than six months between prostate specific antigen tests. He stated:

Bin, j'y pense à tout les six mois pis à tous les ans parce que... j'suis pas capable de faire plus qu'un an sans regarder à mon PSA. Pis là après cinq ans ils disaient, tu peux checker ton PSA à toute les ans pis j'ai toujours été à six mois quand même. Je retournais à l'hôpital pis je disais " Repasse moué donc un autre test de PSA ".

When asked if he thought about his prostate cancer coming back, another participant, Napoléon answered, " *Non, parce qu'on dirait que c'est un peu dernière moué là. Parce que ça va bien, tout est correct. Bin d'après les résultats toujours. Tu te fis toujours à ça, t'sais. Ça fait que non, ça... pas vraiment. C'est pas de quoi que j'y pense à tous les jours disons*".

Similarly, when posed the same question, Quentin also replied, "*Pantoute. So far so good, pis je prends ça comme... c'est tout de bin, je sais pas comment t'expliquer ça, mais ça l'a été pogné en temps*".

For Déjean Jr., the fear of recurrence became a reality on the day before our scheduled interview when he was advised by his urologist that his cancer had returned. Having opted for a combination of hormonal therapy and radiation treatments based on his specialist's recommendation, Déjean Jr. was confused by this recurrence. Emotionally, he explained:

J'étais sur le borderline tout le temps, à .7, .8, même je montais à .9, .10... pis je rebaisais, c'était comme un yo-yo. Et puis quand j'ai parti avant d'aller en Floride j'étais à .8... et puis, quand j'ai revenu de Floride 6 mois après, j'ai pris un PSA, je prends un PSA à chaque fois que je pars pis à chaque fois que je reviens... pis hier il m'a dit que le PSA était à 22. Je ne comprends pas... Ça

supposément que ces piqûres d'hormones là, ils empêchent les cellules cancéreuses de se reproduire. Mais, qu'est-ce que je comprends pas... c'est si ça l'empêche les cellules le cont... de se reproduire, comment que ça se fait ça que j'en ai encore? C'est ça que je vais savoir là, mainque j'aille voir Dr. X, là la semaine prochaine, dans deux semaines, que... s'ils ont pas tout ôté, peut-être qu'il en restait... je l' sais pas! C'est ça que je me pose la question. Parce que quand que Dr. Y... j'ai demandé Dr. Y ... si c'était mieux de enlever la prostate, ou de suivre les traitements. Lui il m'a suggéré des traitements. Il m'a dit que... l'ablation de la prostate... était à 65 % garantie, et puis les traitements étaient garantis à 85 %. Fait qu'on a opté pour les... la radiation. Bin là j'suis au même point que je l'étais vèla deux ans... j'ai encore du cancer. Bin là il me dit que... vu que j'suis à "early stage" peut-être qu'il n'a pas beaucoup. Je sais pas.

Déjean Jr.'s account of his shock and disbelief at the recurrence of his cancer not only pointed to the ongoing trauma this disease can cause; it also highlighted the lack of closure that an initial diagnosis of prostate cancer can impose. For some men within this study, trusting their medical team was central in their treatment decisions and when recurrence occurred, they, like Déjean Jr., found themselves in positions of disbelief. For others however, successful treatment outcomes were viewed as a direct correlation to their decision to comply with their specialist's recommendations. In fact, several men from this study cited medical compliancy in reference to the success of their treatment outcomes and the minimization of their treatment side effects. For example, Hébert shared how he believed that his adherence to his physician's recommendations helped accelerate his healing once he arrived home from his extended hospital stay (due to complications from surgery, as described above): *"Moi, j'ai suivi ça à la lettre (...). Si l'docteur y dit fais ça, fais ça, fais ça, lui 'si y'ai très, très discipliné. Pis moi j'suis faite pareil. Que c'est le docteur me dit, je l'fait."* Stéphane also acknowledged the importance of following medical orders when he stated, *"Il faut que tu suives ce que le médecin il dit, ça c'est un gros point... Il faut que t'écoutes à la lettre. Ils disent, il a une raison. Ils savent eux autres comme... ils parlent selon l'expérience quessé qu'ils ont l'a vue eh... ."* However, participants' accounts also demonstrated that the specific side effects experienced by each participant was dependent on a variety of factors, including the cancer's location, the individual treatment plan selected and each

man's overall health status at the time of treatment. In the following section, a closer analysis of the formal and informal strategies participants utilized when faced with the various consequences of prostate cancer treatment will be conducted in order to ascertain how these strategies impacted their overall quality of life.

5.4 Resilience and Post-Treatment Realities

The previous sections identified some of the major side effects participants faced when diagnosed and treated for prostate cancer. The side effects ranged from mild physical and psychological discomforts to significant challenges. In the following section, a review of the formal and informal strategies participants utilized to maintain, improve or redefine their post-treatment quality of life will be provided. Quality of life will be explored as being a dynamic, multidimensional concept that was regarded and described differently by participants. Notions of how one's masculinity interfaced with sexuality and how men interacted and maintained personal relationships will also be identified as important indicators of quality of life. In addition, participation in community events and the ability to remain productive within their new post-treatment realities will be highlighted as important coping strategies used by some participants. Finally, a broader understanding of quality of life leading to new ways of defining one's value and purpose and the importance of giving back to others experiencing a similar diagnosis will also be shown to be of great importance to many participants in this study.

5.4.1 Redefining Quality of Life

In the introductory chapter of this thesis, quality of life was defined as an individual response to physical, mental, and social side effects of illness that significantly influence the extent to which personal satisfaction with life circumstances can be achieved (Bowling, 2007). A synthesis of the current conceptualizations of quality of life revealed that, by nature, it is a subjective, dynamic, multidimensional concept inclusive of the physical, psychological, functional, social, and spiritual domains (Bahrami, 2011; Cummins, 2005; Hendry & McVittie, 2004). When queried about their perceived quality of life; both prior to and following a diagnosis and treatment for prostate cancer, most participant responses echoed current academic literature. For some, quality of life was related to their physical abilities, their health, their sexuality, or their activity levels; while for others; it was more closely related to their community involvement

and their personal relationships. Still others incorporated a redefined approach to living a quality life which focused more readily on their ability to appreciate the “little things” in life; many of which they admitted to having previously overlooked, taken for granted or undervalued. It is important to note that with an average of 8.6 years having passed since these participants received their initial diagnosis of prostate cancer, their recollected assessment of the impact of this disease on their current quality of life may well have been mitigated by the various coping and adapting mechanisms they have employed. The following sections illustrate, using the participants’ own words, their experiences following treatment for prostate cancer.

5.4.2 Shifting Priorities & Renewed Appreciation

Men in this study offered a muted acknowledgement of changes to their quality of life. For many, a renewed appreciation for life outweighed their admission of the changes endured as a result of their diagnosis for and treatment of prostate cancer. While most participants later acknowledged the impact of prostate cancer on their quality of life; initial discussions referred only to the presence of minor, inconsequential side effects.

Several men cited their belief that being alive was the most important factor in their perception of quality of life. For example, when asked if his quality of life had changed since his diagnosis of prostate cancer, Doménic indicated that living was more important to him than his quality of life: *‘Ben, c’est pas comme c’était avant là... mais comme j’ai dit tantôt, j’t’encore en vie, I’m still talking. The key thing is you’re still here.’* A renewed appreciation for life was also emphasized by Éllie Jr., who stated, *“On apprécie plus chaque journée eh, à 100%, on en profite là aujourd’hui”*. Germain also spoke of a renewed outlook when he suggested:

Moi j’conseil à du monde, comme des fois y s’lamentent y’ont mal pis si pis ça, pis j’dit vous pensez vous allez pas bien, j’ai dit, allez faire un tour à l’hôpital. Vous allez en voir qui s’ont beaucoup plus jeunes que vous autres pis s’ont pas mal. So vous[inaudible] être en santé comme vous l’êtes. Normalement ça fait du bien ça. Quand tu ... (...) Quand tu vois autour de toi là. Tu te demandes pourquoi tu t’lamente.

For Onézime, having good mental health contributed to his quality of life inasmuch as it had always been a priority in his life:

C'est que, ce que je fais à travers le mouvement, pis ce que j'ai vécu en thérapie, j'ai fait deux thérapies, pis ce que j'ai vécu en travaillant dans ce milieu-là, ça m'a amené à être très positif. Je refuse de mourir avant d'être mort.

Other participants indicated that their experience with prostate cancer changed their life in a positive way. Now five years post-diagnosis, and four years post-prostatectomy, Doménic was able to reflect upon his past experience with the disease. He shared:

Hmm ... [souple] [long silence] Tu vois la vie d'une autre manière. Moi j'me trouve chanceux. Mais ... you don't take life for granted anymore. Moi faut j'te dise par exemple, moi je suis un des chanceux, certain y'a d'autres chanceux mais ... J'ai une épouse qu'y a été vraiment supportive. Comme, if I wouldn't have her, probably, I wouldn't be here. Okay? J'réalise que la vie c'est comme ... j'ai quatre enfants, j'ai quatre p'tits enfants, pis c'est pour eux autres que j'vie comme c'est là. Pis ma femme comme de raison. C'est ça tu vois, tu vois la vie d'une autre manière, comme j'm'attache pu à des choses matérielles comme asteure. Parce que j'voie asteure que j'aurais pu passer comme de raison, j'ai encore des problèmes, mais hey ... I'm still talking to you. T'sais, c'est pour ça que j'veut partir un groupe de support pour montrer aux gens que, there's something else afterwards. Don't stop.

Cancer is an experience that impacts all areas of a person's life in ways that most people without cancer could not even fathom. Doménic's account demonstrated how his experience stimulated a renewed appreciation for life and for the relationships he held with those closest to him. Like Doménic, many participants within this study underwent a reassessment of their values and beliefs, life goals and priorities. Such was the case with Stéphane, who spoke of his cancer experience as having forced him to alter the manner in which he looked at life and love. He shared:

C'est euh... on apprend il a bin des côtés qui changent. On... il faut s'enlever dedans la tête qu'on... qu'on est pu bon, il faut... on est encore bons. Mais... c'est... on apprend à aimer de différentes manières. Puis on découvre... on découvre beaucoup plus. C'est pareil comme quelqu'un qui... avant de venir aveugle, il peut pas comprendre, mais quand qu'il devient aveugle il sent, les

bruits, tout ce découvre. C'est un peu la même chose. C'est, on découvre à aimer de différentes manières. On découvre à... à trouver les choses belles, les choses de la nature même. On apprécie plus.

The importance of shifting priorities as a mechanism for adapting to his post-treatment reality was also demonstrated by Léopold when he stated:

Pas de sex mais.... Euh...J'suis pu un jeune coq là moué! (Rire) ... Mais, on est bien icitte, on a une belle grande appartement... proche de tout, un p'tit b... un p'tit buggy à quatre-roues là, je me promène avec ça tout partout pis, j'ai mon char pis... Ah ouais! J'ai 87 ans! Ça va bien. On s'habitue à notre petite vie. Il faut changer de... la routine des fois, parce que... il arrive quelque chose comme là là...Il faut s'adapter à quessé qu'on est capable de faire.

A shift in priorities towards more existential elements of life was a common theme within this study. The consequences, both physical and psychological of prostate cancer compelled many participants to evaluate their lives and to incorporate the experience of cancer into their understanding of themselves and their relationships. Many participants learned to adapt by not taking life for granted and instead, learned to appreciate the smaller joys in life. In fact for many, past troubles and current struggles did not seem as important because they survived cancer.

5.4.3 Supportive Relationships

Supportive relationships, especially with their wives, were important for participants' post-treatment quality of life. Not surprisingly since research has shown that for the majority of cancer patients, spouses are the most significant sources of support for dealing with illness (Lafaye et al., 2014). In fact, marital status has been shown to impact men's overall experience assessment along their continuum of care and has been proven to have a positive correlation with obtaining follow-up care use in long-term cancer survivors (Forsythe et al., 2014).

For some participants, quality of life was not viewed as an end in and of itself, but rather as a guide for redefining their personal interactions with others. In fact, several men cited aspects of family and relationships with others as determining factors in their evaluation of their post-treatment quality of life. For example, Stéphane stated:

Il faut t'aïlles, il faut t'aïlles du support. Si t'sais, si t'as pas de support, parce que c'est pas évident là... Ma femme m'a aidé beaucoup. Beaucoup, beaucoup. Elle a été une partie de mes uh... de revenir... ça l'a été plus facile, que de passer au travers tout seul. C'est sûr. Puis on avait des amis qui venaient nous voir, puis, ça fait... Il faut que tu sois entouré par exemple, pis là... Une personne t'seule c'est certain que c'est pas facile moralement, bin n'importe quelle opération là, mais t'sais j'veux dire...

The importance of spousal relationships was also stressed by Hébert, who recalled:

Nous autres on a très bien passé à travers de d'ça, on s'est entendu. Quand on a, ma femme a dit si la santé va bien, ça va ben aller. Pis c'est d'même ça virer. Là jusqu'à date on a pas rien à dire, pas rien, rien, rien à dire. Oui, oh oui, oui, oui. Moi pis ma femme a tout l'temps des dialogues. On a des bonnes conversations. On a tout l'temps été, nous autres là, dialoguer là, avec nos enfants pis toutes là. On a, on a eu, on a eu des enfants, on a eu des problèmes avec les enfants pis toute. Mais ça tout l'temps été ouvert, on a tout l'temps, tout l'temps été ensemble pour ça là. N'importe de quoi qu'on faisait, que ça c'est dans n'importe quel département. Ma femme est impliquée, pis on s'consulte. Pis euh, t'sais, oh non. Ça c'côté-là c'est que chose. Moi j'ai rien rapproché su c'côté-là, là.

Zachérie also commented on the importance of support systems when dealing with a serious illness like prostate cancer. For him, the support he received from those around him also acted as a catalyst for his recovery. He explained:

I mean, you get support from people that you know... they... they love you, that's why they're taking care of you. And I mean... and then... when you come back, you give a shit... in the work field, and you're thinkingYou know what, these people were good to me... I'll make you proud of (me).

While many people may be affected by the diagnosis of prostate cancer, many participants, like Zachérie, spoke of the importance of being surrounded by supportive others. Whether it was a spouse, a friend or colleagues at work, having access to a network of peers and

loved ones was shown to be of great importance for participants' overall success in adjusting with the changes they experienced because of their disease.

5.4.4 Individual Productivity and Involvement in Activity

Maintaining personal productivity and being involved in activities that were meaningful and rewarding were principal themes in most participants' descriptions of their post-treatment quality of life. For many, quality of life was synonymous with the ability to do and continue doing the things that they loved. While many men from this study acknowledged a change in their physical health and/or functional abilities since the time of their initial diagnosis of prostate cancer, several acknowledged that these changes could be understood in terms of a normal part of aging since they occurred at a time coinciding with a variety of transitions in their lives (e.g. retirement or semi-retirement, transitioning from a home to living in an apartment, etc.). As expected, several participants acknowledged their level of quality of life in reference to their physical health and ability to continue participating in the activities they enjoyed. For Zachérie, the ability to return to work, to go camping and to ride his motorcycle were big milestones in his recovery. He explained:

Once I started getting back into doing stuff that I enjoy doing, right? And I mean, like... it's not just bike riding, it's camping, like, you know... and we have a trailer and we go camping and stuff... and like you know, for a while you're like... you can't really do much and whatever, because... and I mean, once I started getting better, even when I started back at work... it was better.

Likewise for another participant, Germain, maintaining his active lifestyle after he completed his treatments was important. When asked if his quality of life had changed, he shared:

Non...ben... J'ai pas arrêté d'travailler. Un peu moins confortable, mais toujours continuer. Fallait que j'me tienne actif. Parce que, même quand j'avais l'cancer, j'aimais à faire le ski d'fond, la raquette, du skidoo. [...] sentiers d'motoneiges. Maintenant, oh [je suis] beaucoup plus actif, et pis j'continuais à faire les sports que j'faisais.

Hébert provided a very similar account when asked about his quality of life. He expressed feelings that good health, both physical and mental, was something to treasure. In fact, he indicated that his current health status was the best it had ever been. He shared:

Moi j'suis très content, pis j't'en bonne santé. Comme j'te dit, aujourd'hui j't'en très bonne santé. Euh, sa fait quatre ans j't'à retraite. Pis sa fait quatre belles années que j'vie, moi pis ma femme, on voyage pis toute. J'espère m'a n'avoir encore plusieurs, mais c'est ça qu'c'est à peu près, moi ma vie c'est ça.

When asked if his prostate cancer had affected his quality of life, he replied:

Non, j'ai resté moi telle comme j'étais, j'ai pas été, non, non. J'ai pas été, non, ma vie a resté mieux. Pis même, on va dire, on manque de rien, on est heureux même, pis t'sais, ça va bien, pas ... Même j'pense que le couple s'est plus rapproché même je dirais. (...) On s'est supporté ben, je sais pas. Mais t'sais, on est plus, on est plus unies.

A cancer diagnosis can cause a lot of uncertainty and confusion. More so, treatment options for prostate cancer can play particular havoc on both men's live and their closest relationships. However, Hébert's account demonstrated that he and his wife experienced an improved relationship since coping with prostate cancer together and as such; they were able to adjust their views of this disease beyond its negative side effects and to come to see it as a learning experience that allowed them to grow as a couple.

5.4.5 Altruism: Helping the Next Guy

For several participants in this study, part of the process in dealing with their illness experience was to try and help others so they would not experience the same uncertainty or misfortune in the face of a diagnosis of prostate cancer. Literature supports that these types of altruistic coping strategies have a positive impact on the psychological and physical adjustment in men who have been diagnosed with prostate cancer (Roesch et al., 2005). In fact, several participants, like Doménic, shared that their participation in this study was fuelled by a desire to share their stories with others. When asked how he felt talking about his prostate cancer experience, he shared, “*Moi ça me fais absolument rien. Je saque... Ça fais pas de différence qui qui sait que je, que j'dis, j'veux que l'monde... I want my voice to be heard.*” Doménic later

elaborated on his intentions when he described his desire to advocate changes to the cost of prostate specific antigen (PSA) screening in Ontario. Currently, Ontario is one of three provinces — along with British Columbia and Quebec — that does not cover routine PSA screenings under its provincial health plan. More specifically, the Ontario Health Insurance Plan (OHIP) will only cover the thirty dollar charge if the test is ordered by a medical physician for at-risk patients or if a man has already been diagnosed with prostate cancer and is currently receiving treatment. For Doménic, charging men for routine PSA testing is a detriment to early detection and is especially difficult for men living in lower socio-demographic brackets. He stated:

That's what I want. The more the voice is being heard, the more the government is gonna us, uh... Tu sais, sais ça, le gouvernement va nous aider si que... il faut que ça change.

Mobilizing men was also shown to be of great importance to Isodore, who at the time of the interview was heavily involved in his local prostate cancer support group. When asked why he thought having this community network was important, he replied:

Bonne question... c'est important. C'est sure. C'est notre communauté. Notre langue. Pourquoi, pourquoi te privé, pourquoi. T'sais ça finit toujours par la même chose, un cancer c't'un cancer là. Il faut en parler. Aider le prochain. C'est pour ça que je travaille fort avec le groupe de support ici. Les hommes ont besoin de ça. De parler. De s'aider. Moi aussi j'imagine. Ca m'aide aussi j'imagine.

Stéphane also shared that he felt there was a benefit to having a safe place where he could ask questions to others who have experienced a similar diagnosis. He explained:

Souvent quand qu'on faisait des téléconférences, j'ai trouvé ça bon aussi. Il avait du monde qui avait la même question, pis il était gêné de la poser, bin là il l'entendait, ils avaient pas besoin, ça l'avait rempli leur réponse. Leur question, t'sais, ils savaient, il avait pu besoin de le demander eux autres même, c'était déjà un soulagement.

However, not all participants saw the need to gather with others to talk about their disease. Léopold, for example, did not identify with the perceived value of participating in a support group. When asked whether he attended the monthly meetings, he replied:

Non. Non moué j'aime pas ça parler de ça. Mon trouble à moué là, je le garde pour moué... S'il m'en parle, j'va dire " Mais uh... ça va venir, ça va venir! " Mais t'sais pas pour... non j'aime pas parler... des mes troubles. (...) Quessé euh... quessé que je voulais dire à ça là? Des fois tu vas conter ça à quelqu'un, pis lui il va le conter, mais il le contera pas de la même manière. Ça fait que là ça fait... " Tien, J il est pris du cancer, pis là il est magané... " pis ah! Ils t'overload pis... ah...

Prostate cancer support groups have prevailed for more than 20 years in Canada providing support to men with prostate cancer and their families (Garrett et al., 2014). While accessing such support groups in smaller, more rural communities was viewed as more challenging, many participants acknowledged the importance of having choices in relation to how they accessed support (e.g. seeking formal advice from their family physician, speaking to other survivors, accessing relevant literature or the internet). While participants offered a variety of accounts in relation to what they found helpful or not during their illness experience, most offered some form of advice for others.

5.5 Chapter Summary

In this second results chapter, health service inefficiencies that participants from this study were forced to mitigate were identified. In addition, a closer look at the physical and psychological side effects of treatment for prostate cancer and their direct impact on participants' resilience and perceived post-treatment quality of life was taken. While their accounts mainly focused on their need to manage and adjust to the adverse side effects of their treatment decisions, strategies used were shown to transcend all stages of the illness experience. Participants' accounts represented a range of emotions, experiences and adaptive strategies coherent with a fluid understanding of resilience, whereby individuals coped and adapted in order to reconcile themselves with their unexpected life circumstances. The following chapter will provide a detailed discussion on the influence of location, culture and language on

Francophone prostate cancer patients' resilience and quality of life following their diagnosis and treatment for the disease. In addition, a visual illustration of their accounts will be provided.

CHAPTER 6: DISCUSSION

This thesis project began around the same time that the Honourable Jack Layton, then Leader of the Official Opposition-New Democratic Party of Canada, announced that he was temporarily withdrawing from politics in order to treat a new cancer recurrence following an earlier diagnosis of prostate cancer. Initially diagnosed with the disease in February 2010, Mr. Layton's openness and candour fostered open discussions about the disease. As a great supporter and advocate, he showed great commitment and strength to the cause. His untimely death was a difficult testament to the seriousness of prostate cancer. His experience as demonstrated within the current literature is a fate that one in eight Canadian men face and one in 28 will succumb to in their lifetime (Canadian Cancer Society, 2014).

Although the increased interest in both academic and biomedical studies of prostate cancer allows for greater discussion on the topic of the disease, current research does not compel us into action. More specifically, since available research mainly focuses on statistics, diagnoses and prognoses; it limits our ability to understand how prostate cancer affects men on an individual level, within their intimate couple dynamic and within their broader community. As attested to it throughout this thesis, prostate cancer inevitably forced respondents to reconstruct their lives within a new reality of uncertainty. This thesis, which I embarked upon just as Mr. Layton lost his battle to cancer, was conducted among men who had survived the effects of their prostate cancer diagnosis and sought to uncover participants' unique cancer experiences while also drawing attention to some of the cultural and sociolinguistic specificities that they faced by virtue of belonging to a particular linguistic group within a northern community setting. Hence, this study focused on exploring the realities of Francophone men from Northeastern Ontario, who, as we have clearly shown, were required to manage a potentially life threatening disease within a health care service delivery model that did not always respond to their particular needs.

Described within a context of resilience, this study revealed the limitations of our current health care system and demonstrated various strategies participants employed in order to cope, adapt and/or overcome them. Participants' accounts of their realities following their cancer experience were also presented within the context of quality of life; whereby they constructed

and reconstructed their own definition of quality of life at the very moment when they were at the greatest risk of losing it. As illustrated by various accounts throughout this thesis, experiencing a diagnosis of, and treatment for, prostate cancer extended far beyond the medical implications of the disease. In fact, recognizing the subjectivity of each man's illness experience was fundamental to understanding the importance of the social and cultural imperatives that shaped participants' interpretation of their particular disease experience.

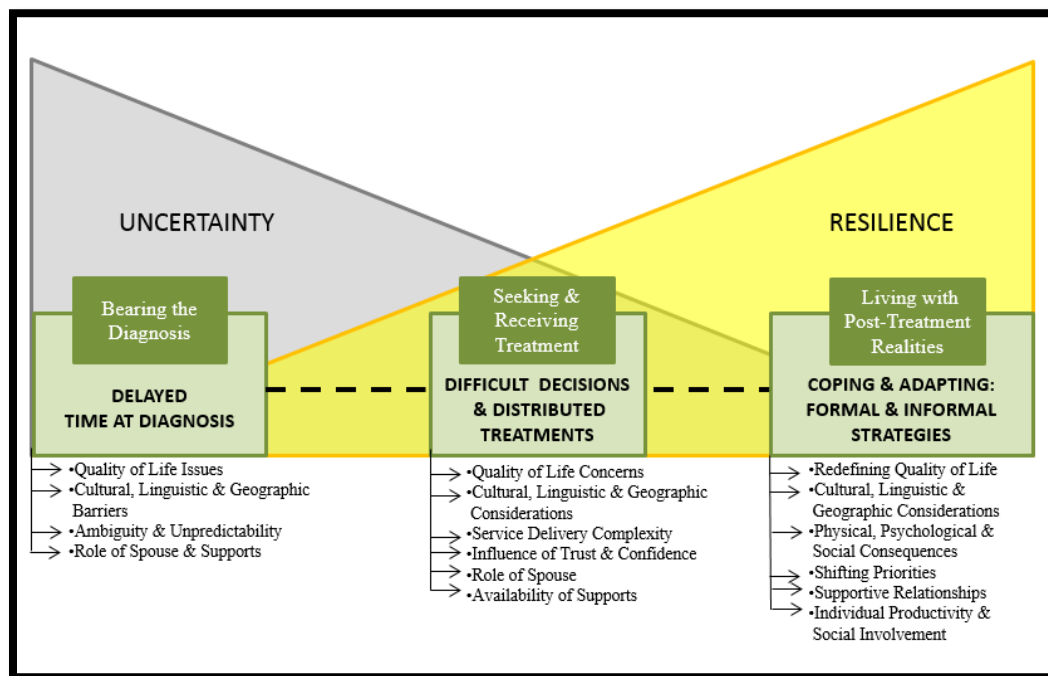
As previously identified at the beginning of this thesis, the main objectives of this study were to uncover the impact of a diagnosis of prostate cancer and the uncertainty it generates on Northeastern Ontario Francophone men's overall quality of life and the resilience they demonstrated during various points of their illness experience. Furthermore, this study hypothesized that: 1) as a result of various cultural (beliefs, cultural masculine ideals, language, etc.) and geographical (isolation, distance, etc.) factors, participants delayed their entry into the health services system, thereby delaying their time of diagnosis and negatively impacting their overall post-treatment quality of life; 2) that both language and culture were key factors in understanding how they constructed (and reconstructed) their illness experiences; and 3) participants utilized a variety of informal strategies to overcome the barriers they faced within the health care delivery model and that these strategies helped them redefine themselves and their lives in the face of this disease. Results clearly articulated influence of location, language and culture on participants' experiences and highlighted the myriad of feelings and emotions they endured upon being diagnosed with a potentially life-threatening illness. Findings from this study demonstrated the range of obstacles each man faced upon being diagnosed with the disease that supported the presumed hypotheses. While most accounts pointed to feelings of shock, fear, anger, anxiety and uncertainty; the experiences disclosed by Francophone prostate cancer patients from Northeastern Ontario highlighted the challenges they faced when attempting to manage their disease within a health care delivery model that is incapable of meeting their unique linguistic and cultural needs.

Prior to delving more deeply into a discussion on the influence of location, culture and language on participants' resilience and quality of life following their diagnosis and treatment for the disease, a visual representation of their accounts will be provided. Figure 1 (below) thus offers a schematic representation of the broad parameters of participants' illness trajectories as

described by them during the course of this study; recognizing that the degree and duration each participant endured within the various stages were subjective and bore witness to their individualized constructions (and reconstructions) of the events. A narrative description of this dynamic representation follows:

Figure 1

Francophone Men's Socially Constructed Prostate Cancer Illness Experiences



Within this study, Francophone participants' prostate cancer experiences were analyzed in reference to their disease trajectory; mainly from the time of their initial diagnosis, during the period where they sought, selected and received treatment, and, during the post-treatment period of living whereby participants adapted (to varying degrees) to their new realities. For the sake of clarity, the information presented within this conceptual model also follows this chronological schematic while also recognizing that each man's experience was necessarily influenced by a

myriad of factors. In other words, while the temporal categories existent within illness experience can offer clarity in terms of the broader conceptual narrative, they are not meant to be understood as mutually exclusive or temporally fixed. Rather, each trajectory is understood as being fluid in nature since participants' recounted experiences often exhibited fluctuating patterns of manifestation.

Beginning at the far left of this model, we start with the time of participants' initial diagnosis of the disease. This period was described as a time of great uncertainty for most men who offered accounts of great uncertainty often attributed to the ambiguity, complexity and unpredictability of a disease that many had been unfamiliar with up until their diagnosis.

Within the results of this study, quality of life issues first emerged in response to the fear men expressed when describing the risk this disease posed to their current condition. In addition, it was recognized that as participants' reactions to the news of their diagnosis and their initial concerns related to their quality of life were interactive, with each having great influence on the other (e.g., life circumstances changed their current and projected quality of life concerns in as much as their quality of life affected their life circumstances). In addition, as previously established, quality of life was understood as a socially constructed concept that encompassed a variety of dimensions within a person's life such as their general well-being (e.g., physical and psychological health), their access to healthy social connections and feelings of social usefulness, their spiritual well-being, their ability to fulfill their life's goals, their overall happiness, as well as their overall satisfaction with life.

While participants' initial reactions to their diagnosis of prostate cancer were as varied as the men themselves, the overall theme of delayed time of diagnosis, most often caused by a belated entry into the system, emerged. These perceived delays were reflective of both individual factors (e.g., respondents being in denial with regards to their symptoms, lack of knowledge on what the symptoms were, or participants lacking symptoms altogether) and larger health care delivery issues prevalent within many of the smaller Northeastern Ontario communities (e.g., lack of primary and secondary care services within their community, greater climatic and geographical barriers to accessing care that was only available outside their home communities). Participants also acknowledged the influence of cultural barriers that negatively influenced their

time at diagnosis such as their avoidance of health services, or their need to maintain a culturally appropriate masculine persona (e.g., some symptomatic participants described their own delays or refusal to seek assistance based on their fear of how others would react because of it). The role of spouses and other supports, especially participants' family physicians and other friends/acquaintances who had experienced a similar health situation, were also shown to be extremely influential in men's construction of their social realities at the time they were first diagnosed with the disease.

Upon receipt of the news that they had prostate cancer, many participants described a period of continued uncertainty related to the process they endured in seeking and ultimately receiving treatment for their disease. In fact, many men in this study alluded to the fact that their treatment choices were largely based on their fears related to their quality of life, which most often surrounded the potential physical side effects associated with various treatment modalities. However, while quality of life concerns were key considerations in their treatment selection process, many participants opted for treatment plans based on informal recommendations of past patients or friends within their community. In this sense, cultural imperatives that constructed the social context of men's lives largely influenced how these particular men chose to manage their disease. In fact, personal and familial referrals were understood as being of almost equal importance to the clinical recommendations provided during most medical consultations. Information gathering on potential treatment methods was seen as being facilitated or hindered by men's language comprehension skills. For unilingual Francophones, the use of supports (often spouses or adult children) was key in enabling participants to understand the complex medical jargon often only available in the English language.

Participants within this study shared a variety of accounts that pointed to the diverse and complex decision-making process they encountered in order to obtain treatment for their prostate cancer. In addition to decisions related to the actual treatments available (and the potential consequences of these treatments on their quality of life), many participants were forced to mitigate an additional level of decision-making related to the nuances of a complex health service delivery system in Northeastern Ontario. Decisions related to the distance and location of the treatment centre, the language spoken by the medical teams working at the treatment centre and the availability of supports within treatment communities were shown to greatly influence

men's decisions. In addition, spousal support and preference also deemed as being very important in their decision-making process. Participants, and their respective spouses', capacity to trust in their medical teams and in their selected treatment regimen (despite the potential consequences these treatments could have on their quality of life) was shown as a key component during this stage of their illness experience. This in turn, often led these men to regain a certain sense of control over an often unpredictable disease.

Participants within this study demonstrated increased resilience as they endeavoured to cope with the physical, psychological and social consequences of their treatment decisions. In fact, they offered accounts of both formal and informal approaches used in order to adapt to living with their post-treatment realities. For some, this involved a re-evaluation of their current priorities and relationships. For others, it comprised of a complete redefinition of quality of life; whereby their previous ideals were transformed into new beliefs, and shifted priorities. For many, quality of life became a measure of their individual productivity, social involvement, and continued relationships. Participants' acceptance of their identity of self and their post-treatment lives were also shown to be greatly influenced by their supportive others, including spouses, adult children, friends and broader community members.

The openness and candour of participants' accounts were somewhat unexpected given what had been presented in the literature (Miller, McKeever, & Coyte, 2003; Roulston, 2011; Zanchetta, Perreault, Kaszap, & Viens, 2007) regarding the difficulties in recruiting respondents for in-depth qualitative studies. More so, in view of the sensitive nature of prostate cancer's impact on men's bodies, their sexuality, and their overall health, I anticipated resistance from those called upon, even if they had agreed to participate. However, during the data collection phase, participants provided detailed and uncensored narratives of their illness experiences; including painful recollections of the realities of this disease on their bodies, relationships, and their mental health. Perhaps this is one of the great strengths of this research project, since as a researcher, I was able to overcome some of the potential data collection difficulties when studying sensitive subject matters, such as prostate cancer which targets the core of men's masculine identities. Through a constructive process and research design that was based in mutual respect, and by virtue of having displaced myself to participants' home communities, I believe this study offered men an opportunity to share their stories in a location, language and

manner that both respected their need to be heard and their desire to help others who may be faced to deal with similar illness experiences. The ease with which participants shared their private struggles and victories in the face of their prostate cancer is perhaps indicative of a shift occurring within society's understanding of this disease as well as a marker of the value of a culturally, geographically and linguistically appropriate research design protocol.

Moving beyond the fear once held surrounding prostate cancer's social stigmatization associated with the physical changes and suffering caused by this disease, more and more prostate cancer survivors are acknowledging their diagnosis and disease, as well as its impact on their quality of life. In turn, this wave of openness and honesty is facilitating an open dialogue within the public domain regarding the realities faced by these men. In addition, while certain literature may sometimes describe older men as avoidant or indifferent in the face of their health (Creighton & Oliffe, 2010; Dale; Arber & Davidson, 2003; Sartor, Davis, & Bennett, 1999; Tannenbaum & Frank, 2011), results from this study argue against such a simplistic depiction. While some men may have been more likely to share their stories by virtue of their connection with prostate cancer support groups, others offered very personal reasons for their participation such as their need to *say it out loud* or their need to move beyond the experience by letting go of it. In fact, the resulting conceptualizations of participants' experiences with the disease were only made possible because of these men's willingness to participate, and their desire to be heard, to have a voice, and to help the next guy. These men's interpretive process and their understanding of their subjective experience with prostate cancer extends beyond the challenges associated with a cultural measure of worth against an idealized masculinity to include a sense of meaningful contribution as they share their experiences with others.

With the ongoing social and cultural campaigns targeting open dialogue with men about their health, more and more men are feeling comfortable discussing the physical, psychological and social side effects of their disease. In the wake of large fundraising and promotional campaigns such as *Movember*, where men are invited to grow a mustache during the month of November in an attempt to bring awareness and raise funds for prostate cancer research and depression awareness, and with the advent of more celebrity illness disclosures, such as Mr. Layton's, society is becoming more aware of this disease, its risk factors and the importance of

managing one's own health. However, while prostate cancer awareness and research have come a long way, there is still much work to be done.

6.1 Northern Realities: Geography, Culture & Language

The reality of the current health care delivery model imposes a variety of constraints on men's ability to take charge of their health and once diagnosed, manage their disease.

Participants within this study are but an example of a broader context; a representation of a larger circumstance that is currently being experienced with our health care delivery model. The information shared within the parameters of this study exposed prostate cancer from a unique vantage point allowing the reader to experience first-hand accounts of how this disease is lived within the current health care system in our northern and rural communities.

Does living in the north play a role in the situation these men experienced with their cancer? Undoubtedly! Participant accounts emphasized the realities of health care provisions in the north. Circumstances associated with the extensive geographic distribution of Northern Ontario's population mass were cited. These included accounts of the impact of geographic isolation, lack or limited health service availability, inclement weather and road conditions on accessing and obtaining quality health care services. While our health care system purports itself as being comprehensive and accessible the discrepancies surrounding the provision of health care services within northern and rural geographic areas have been well established within the literature (Martin Misener et al., 2008; Pong, Pitblado, & Irvine, 2002; Pong & Russell, 2003; Romanow, 2002). Participants within this study faced many challenges related to accessing health services within smaller, northern and rural communities. They described situations of delayed access into the health care system for various reasons such as the lack of primary and specialized health care professionals within their communities. The dearth of family practitioners and general practitioners within Northern Ontario is well recognized. Results from a study by Wenghofer and colleagues (2011) found that while the province of Ontario may not be underserved in relation to the *absolute practicing physician-to-population* ratio, the actual number of practicing primary care practitioners is disproportionately located within the province's urban locations thus causing a situation of inequitable service provision among Ontario's northern and rural communities (Wenghofer, Timony, & Pong, 2011). More specifically, results from their analysis included the entire Ontario physician population which

found that a disproportionate amount of physicians (71%) were practicing in urban areas where only 59% of the total population resided (Wenghofer et al., 2011). While it is well known that general practitioners within more northern and rural communities possess larger scopes of practice (Hutten-Czapski, Pitblado, & Slade, 2004), the influence they held and support they provided to the men who partook in this study extended beyond what is generally referred to in the literature.

While it has been documented that being confident and placing trust in one's medical team can positively impact patient outcomes (Gopichandran & Chetlapalli, 2013), the experiences described by participants in this particular study extended far beyond the type of trust a patient would place in someone solely because of their professional expertise. In fact, when speaking of "trusting their doctors," participants often referred to their familiarity with their doctor outside of the medical office. Within many small towns, it is not uncommon for the family physician to hold an important role within the social fabric of the community. For example, participants described "trusting" their family physician because they were part of the same social circle, they volunteered together, or they were friends who had gone to school together. While there certainly remains an ever-present need for more primary care professionals in many of our northern communities, men in this study spoke of the benefits of small-town care in that they felt they had even more access to their family doctors than they would have in larger cities. For them, access did not refer to the ability to obtain an appointment with a particular doctor; rather, it referred to their ability to have, and to maintain, an extended relationship with their doctor throughout the various stages of their lives. While these men in particular may have had little or no prior exposure to the health care system per se, they were more familiar with their family doctors because of the social and community interactions they had with them in their social circles (e.g., immediate and extended family, friends, neighbours, etc.). Their doctor's reputation extended far beyond their interactions within the medical office environment and included a much broader social network in which both the physician and the patient belonged.

The accounts shared in this study reflected the reality of medical practice in northeastern Ontario, where lack of access to specialized services often translated into an expanded scope of practice for those working within these communities. In order to gain a true understanding of the realities of the experiences men had in the face of their diagnosis of prostate cancer, it was

important to research the construction of their illness experience within the larger parameters of its occurrence. Men did not construct and reconstruct their understandings of their pre- and post-cancer experiences independently. They were constructed in reference to the place, people and things that surrounded them during the various phases of their illness. More so, accounts presented within this study demonstrated the contradictory relationship that existed within men's social constructions of their quality of life and of their resilience. In other words, participants' potential loss to their quality of life was the catalyst in the development of their resiliency within their illness experience. In addition, the social and cultural relationships that patients experienced with their health care professionals (e.g., physicians, specialists, nurses, radiation technologists, etc.) were often weighed as importantly in men's accounts of the quality of service they received in their individualized treatment outcomes.

For example, the information shared by the spouses who voluntarily attended their husband's interview also shed light on the need to consider the potentially deleterious impact of prostate cancer on not just familial and social networks. Spousal testimonies reinforced the fact that for many of these participants, their experiences with this disease were either helped or hindered by the reactions and adjustments (or maladjustments) of their loved ones with their disease. While the cancer patients experienced the physicality of the disease, their wives (and to some extent their adult children) also suffered the consequences of the diagnosis.

As a researcher, I was most surprised by the level of candour many participants and their wives offered during our interviews. In fact, when one participant's spouse spoke of the changes to her husband's unique smell and its effect on their intimacy outside of the bedroom, I too was forced to reconceptualize my understanding of intimacy within the quality of life paradigm as opposed to the standard sexual functioning definition often cited within the literature. In recognizing that couples may also have redefined their roles within their relationship both as a measure of adapting and coping with the disease as well as a mechanism to preserve their own intimacy, I was compelled to expand my own understanding of the broader context of the parameters of personal management of the consequences of this disease. In addition, participant accounts of the facilitation and assistance they received from their adult children clearly demonstrated the need to make resources and services available to the broader network members who may play an important role in the survivor's care and adjustment. Understanding the role of

the spouse and supports, including that of adult children and close friends or relatives, are topics yet to be fully developed within the research literature.

As much as the availability of family and social supports were important in men's ability to cope and adapt to their cancer; the relationships they had with their family physicians prior to their diagnosis, either directly or via a small degree of separation, were also often cited as a reason why they were happy or satisfied with overall prostate cancer experiences. While the importance of the role of family physicians in participants' constructions of their cancer experiences and post-treatment realities cannot be overstated, it is also important to discuss the potential conflicts that these inter-dependent roles can play for patients within smaller communities. In fact, some participants shared stories of delayed time at diagnosis, not because of a lack of access to a primary care practitioner or to specialized care, but because of an over familiarity with their community physician. Given the sensitive nature of the side effects of prostate cancer and the uncomfortable nature of the screening tests for the disease (e.g., primarily, the digital rectal exam), being "friends" with your family doctor could, in fact, be a barrier to both the patient seeking medical assistance and for the physician to routinely request and perform physical examinations on the patients. When physicians are members of a small town community, especially ones where cultural beliefs are so heavily embedded within the social practices, there could be the potential for contextual ambiguity within the professional-patient dynamic causing discomfort and embarrassment. Although both parties may not even be aware of the hidden subtleties challenging the roles each person plays within the health care exchange, the increased familiarity physicians have with their patients (and vice-versa) could inadvertently influence their dynamic thus creating challenges for both the patient in terms of their comfort in disclosing sensitive information (Oliffe & Thorne, 2007; Shahidi, 2010), and for the physician in terms of maintaining appropriate personal-professional boundaries (Abbott & Luke, 2011). While professional ethics and standards most certainly reign within any patient encounter, the intimacy or informality many patients described having with their family physicians may have positively and/or negatively impacted the care they received. In fact, the current realities surrounding health care delivery within many of our small, northern communities may strip away a certain the veil of anonymity that patients would welcome when dealing with the offensiveness and vulnerability caused by this particular disease. Further

exploration on the impact of fluid relational dynamics between practitioners and patients within smaller community settings may facilitate a better understanding of some of the unique challenges both parties face (consciously or not) within the provision of quality health care.

In addition to the realities facing health service delivery within many of our northern and rural communities, Francophones may face even greater barriers in accessing quality French language health care services. As demonstrated within the accounts provided within this study, participants faced several challenges in attempting to access health care services for their prostate cancer such as the distance and incurred costs associated with extended travel to specialized health care centres. These challenges were compounded in situations where participants wanted or required these specialized services to be delivered in the French language; highlighting a certain level of incongruity in the provision of health care services for Northern Ontario's Francophone patients.

Participants from this study included older men from a particular generation where the French language was central to their everyday lives. In fact, many of these men possessed very little formal education, spoke minimal English, and had very little prior exposure to the health care system. For them, hearing news of their diagnosis was akin to being forced into a new world where their lack of understanding and inability to process the information being provided to them left them feeling vulnerable and exposed. During their diagnostic meetings with primarily English-speaking specialists, participants were often recommended to research their treatment options online or refer to some form of medical documentation being provided to them; most often in written English. While conducting online research may be mainstream, many older Francophone participants noted their inability to navigate the internet, let alone be in a position to properly assess the plethora of information available to them online. According to the World Health Organization (1998), health literacy goes beyond the patient's ability to "read brochures and make medical appointments" (World Health Organization, 1998, p. 10). Rather, it represents the cognitive and social aptitudes required to gain access to, understand and use various forms of information in manners that promote and maintain good health (Tobias-Machado et al., 2013). Thus, participants who possessed lower levels of literacy could also have been affected by a severe lack of comprehension of prostate cancer terms and treatment terminology and as such,

would have found themselves in even more precarious situations of increased fear, anxiety and uncertainty.

Language is an intensely cooperative form of interaction. Embedded with cultural nuances, language is the social glue of conversation that allows people to connect, share, understand and be understood. The rhythm of dialogue between patients and health care providers is an important component to consider when studying the influence of language on patients' illness experiences; especially in situations where there is a language barrier, but patients try to manage on their own. Since language is the primary venue in which culturally-embedded social interactions occur, linguistic barriers can result in serious misunderstandings between the patient and the physician.

A recent study by Bouchard and colleagues (2012b) found that older Francophone patients were more comfortable expressing themselves and being addressed in French since their overall assessment of their encounters with health care professionals were directly linked to their ability to communicate effectively (to understand as well as to be understood) (Bouchard, Gagnon-Arpin, & Makvandi, 2012). In other words, when patients can communicate in a manner in which they feel heard and understood, they are more likely to leave that experience with a sense of confidence in the outcome of the encounter. Bouchard and colleagues (2012b) recommend that health care providers actively offer services in French, stating that elderly Francophone patients would be more likely to speak in their own vernacular (thus reportedly be in a position to both understand more and be better understood) if they were addressed in French at the beginning of the medical encounter (Bouchard et al., 2012b).

To this effect, Benoit and Dragon (2013) propose the benefit of standardized professional translation (or interpretation) service allocations within linguistic minority population communities as a means of increasing the efficacy of the interactive patient-physician encounter where language issues exist since the professional interpreter (or translator) could engage as a neutral facilitator with the skills to assist in communication dynamic. Although formal interpreter service allocations may prove financially and systematically challenging within many of our smaller northern communities that are faced with ongoing health human resource challenges, a hybrid version of this service could potentially be offered via telephone whereby a

trained, third party linguistic support professional could be included, upon request, in medical appointments. Additional research on the use of technological innovations to increase access to culturally and linguistically trained support resources would be required to better determine the potential implications of this type of service for Francophone patients.

Surprisingly, Ontario boasts a large number of self-reported French-speaking family physicians and general practitioners. In a population-based analysis of the 2007 College of Physicians and Surgeons of Ontario Annual Membership Renewal Survey, Gauthier and colleagues (2012) found that there is one French-speaking family physician or general practitioner for every 297 Francophone patients (Gauthier, Timony, & Wenghofer, 2012). However, this study also found that most of these French-speaking practitioners were practicing within Southern Ontario communities where the French-speaking patient ratios were very low (Gauthier et al., 2012). Undoubtedly, a shared vocabulary is an essential component for successful communication. In high-intensity situations such as those described throughout this paper, the ability for both the physician and the patient to understand both the subtle signals and social meanings present in any linguistic exchange is imperative for an effective dialogue to occur. Conversations of a sensitive nature, by virtue of their emotionality, require a forum in which all parties can share information, understand and be understood.

However, access is not the only consideration in reference to the linguistic element of medical encounters. In fact, having a French-speaking physician does not necessarily guarantee that the medical conversations will occur in the French-language (Benoit, Bouchard, Leis, & Garceau, 2012; Bouchard et al., 2012; Bouchard, Makvandi, Sedigh, & Van Kemenade, 2014a). In effect, many participants within this study conceded that even with their Francophone and/or French-speaking physicians, many of their cancer-related medical discussions occurred in the English language or in a combination of both English and French. Since understanding medical terminology is in itself a difficult endeavour for many cancer patients (Pieterse, Jager, Smets, & Henselmans, 2012), doing so in a foreign or second language (or limited capacity) language can undoubtedly add increased stress and uncertainty for men already facing a difficult situation. In fact, Chapman (2003) examined lay understanding of cancer-related terms oncologists use (e.g., medical jargon, such as technical terms or ambiguous language) when discussing cancer diagnosis and prognosis with their patients and found understanding to be suboptimal and

variable (Chapman, Abraham, Jenkins, & Fallowfield, 2003). When a lack of knowledge of medical terminology is further compounded by a language barrier, patients often do not correctly understand their diagnosis, prognosis, or treatment options (Bernhard et al., 2012; Bosco, Halpenny, & Berry, 2012; Bouchard, Chomienne, Benoit, et al. 2012; Butow et al., 2012). However, research has also shown that many elderly Francophone patients lack the confidence to request medical services within their own language (Bouchard et al., 2012).

Although protected under the Canadian Constitution, Francophone patients, either by nature of their fear and anxiety in the face of a medicalized domain for health care, or by their own cultural beliefs that their minority status necessitates they confine themselves to the majority language; they don't ask for French service. Further research would be required to ascertain if French-speaking physicians, who were shown to be central in participants' accounts of their constructions of their illness experiences, actively offer their Francophone patients services in the French language or if they too, succumb to the majority language of medical education, which in Ontario is primarily English.

6.2 Adaptively Overcoming Barriers

As previously described in this thesis, participants also described various formal (e.g., institutionalized translator services) and informal strategies (e.g., online research, reading books/articles on their disease and its treatment options, sharing with friends and family members, focusing on the positive aspects in their lives, etc.) they used in order to prevail over the cultural, linguistic and geographic barriers they encountered. Participants' resilience can therefore be understood in conjunction with their decline in quality of life and the reconstruction of their quality of life necessarily occurs within the context of their culture, language, choice of medical professionals and socio-geographic circumstances. For the most part, the approaches participants assumed were shown to be reflective of the physical and psychosocial side effects they experienced post-treatment, and of the success of these adaptive strategies were shown to affect their present day lives positively. In other words, participants' ability to achieve or maintain a sense of quality of life regardless of the way they chose to construct its definition, was linked to the resilience they displayed in the light of their illness diagnosis and its effect on their

post-treatment lives. With an overarching focus on recovery, on beating the odds, and on moving forward, clearly showed that participants articulated their intention and desire to return to some sense of normalcy post-treatment. While this resiliency in the face of the disease may have represented a new or redefined conceptualization of quality of life, most participants demonstrated an ability to mitigate their life circumstances by renegotiating their perceptions and expectations related to their personal quality of life.

While individual strategies for overcoming the effects of a diagnosis of and treatment for prostate cancer have been shown to positively impact patients' overall assessment of their illness experience, the question raised must include how the broader health system can change to better support Francophone prostate cancer patients from smaller, northern communities? Can a system designed to treat all Canadians recognize and address the needs of a geographical and linguistic minority population effectively? Borrowing from the "aging in place" literature, it is my belief that health care services within Northeastern Ontario could benefit from elements of a personalized health care delivery framework proposed by Eric Dishman (2013).

When considering the barriers and challenges that Northeastern Ontario Francophone prostate cancer patients in this study faced during their illness trajectory (e.g. travelling great distances multiple times in order to access specialized care), there is no denying of the flawed nature of Ontario's current health care delivery model. When access to specialized health care is required, as is the case for most cancer patients from remote and rural communities in Northeastern Ontario, this extended distance to treatment is made even more challenging by the geographical considerations (e.g., poor winter driving conditions, poor highway conditions) that exist within these regions. Putting increased time and financial burdens incurred aside, this distance to specialized care is further exacerbated by the increased wait times caused by the lack of specialized Francophone health care practitioners in the northern communities. Although system-level recommendations may appear relevant in this discussion, could such broad-based proposals be practical? Unfortunately, this may not be the case. While having access to more Francophone (or bilingual) health care professionals within Francophone communities would appear to be an important step in the right direction, it is also important to recognize that population numbers play an even greater role in establishing service needs within all communities, regardless of the culture or language of the local people.

The Northern Ontario School of Medicine (NOSM), with dual campuses in Sudbury and Thunder Bay, is one example of how the government is supporting initiatives to help train, recruit and retain health care professionals who are from the North, will train in the North and will (hopefully) return to practice in the North. With a social accountability mandate that includes a provision of support for the Francophone population in Northern Ontario, NOSM graduates (e.g., undergraduate and postgraduate medical education programs, physician-assistant program, dietetic internship program, etc.) who return to their home communities to practice, are undoubtedly alleviating some of the health care access burden within these communities. With more primary care practitioners, more patients can gain access into the system via a community link within their hometowns.

The personalized model of health care delivery, as proposed by Dishman (2013), offers yet another suggestion to meet the needs and overcome the barriers of health care delivery within our northern communities. Borrowing from the aging-in-place literature, Dishman (2013) advocates the use of a personal health care delivery framework that would allow patients to access quality health care from specialists practicing anywhere in the country, through the use of innovative technologies (Dishman, 2013). Telemedicine initiatives, such as video-streamed consults or diagnostic meetings, could extend opportunities for Francophone patients to access the specialized services they need while remaining in their home communities where access to real-time health coaches, supportive health care staff and social support networks, in their own language, could be more readily available to them. Currently, the Northeast Local Health Integration Network is leading another innovative program is currently called Telehomecare Northeast Local Health Integration Network (Northeast Local Health Integration Network, 2014a). Co-funded by the Ministry of Health and Long-Term Care and Canada Health Infoway, Telehomecare is a new distributed technology-based service that offers health monitoring and coaching for patients with chronic diseases by trained registered nurses. Although this first phase of this program's implementation is for patients with chronic obstructive pulmonary disease or chronic heart failure, future program expansion could include other long-term chronic conditions such as prostate cancer. As a collaborative approach to health care, Telehomecare could, for example, facilitate prostate cancer patient's post-diagnostic experiences by offering them access to a health care professional between their initial medical appointment and the treatment

appointment. As an allied health professional, these registered nurses could coach prostate cancer patients throughout their cancer experience which could lead to better information sharing, better continuity of care and greater patient support from all levels of the health care system. Since this program is not anchored by geographic boundaries, Francophone patients in northern and rural communities could obtain easier access to French speaking health care professionals in the comfort of their own homes.

In addition, the use of innovative programs such as telemedicine and telehomecare could allow for an expansion beyond the current biomedical paradigm of isolated specialists doing “parts care” and instead shift personalized health care management to multidisciplinary teams doing “person care” (Dishman, 2013). In recognizing the social and cultural contexts of health service delivery within northern and rural communities, the health care system could capitalize on the various formal and informal social networks prostate cancer patients’ access when faced with the challenges of a diagnosis and treatment for this disease.

In addition, by acknowledging the increased scope of the role of the health practitioners within many northern communities, health promotion and communication strategies could be better adapted in reference to patient support and education, as well as within community-based health promotion initiatives. With the ongoing debate regarding the merits of screening for prostate cancer, it is my belief that health care professionals must steer away from focusing on intervention, and instead move towards health promotion and education. While screening can be a valuable tool, there is also merit to endorsing educational initiatives that would be linguistically appropriate and socially relevant. In addition, acknowledging the important role culture plays in understanding patients’ perceptions and encounters with the disease, their expressions of concern, and their relationship to individual physicians and the health care system in general are the first steps towards improving patient outcomes.

While the Ministry of Health and Long-Term Care, and more specifically the Northeast Local Health Integration network through its delegated authority, is committed to following the legislative requirements of the French Language Services Act, 1986, which guarantees the right of French speaking Ontarians to communicate with the government and receive services in French; the Northeast LHIN has extended this commitment with the inclusion of an integrated

concept for the provision of French language services within their 2013 - 2016 Integrated Health Services Plan (IHSP) (Northeast Local Health Integration Network, 2014b). Guided by this identified focus on Francophone health issues within the NE LHIN's strategic direction, the importance of research and advocacy related to our Francophone population is being recognized. In addition, through ongoing partnerships with academic and community researchers such as the Consortium National de la Formation en Santé (CNFS) and the Réseau du Mieux-Être Francophone du Nord de l'Ontario, progress is being made to advance the understanding of Francophone health and service provision issues within the various levels of government. Through an ongoing commitment to recognizing and researching the cultural and linguistic factors impacting the access and provision of health care services for Francohpones within our northern communities, it is my hope that this study will act as a springboard for further research and dialogue.

CONCLUSION

The intent of this thesis was to uncover participants' subjective accounts of their prostate cancer experience and the impact this disease has and uncertainty it generates on their overall quality of life. In allowing participants to voice their journeys in a manner that included and respected both their linguistic and cultural affiliations, we were able to capture the significance of their situations. While participants in this study constructed their experiences with the disease and thus their understanding of its impact on lives in reference to various personal, social and cultural contexts; collectively, their stories depicted the realities faced by many Francophone patients who are faced with specific challenges when obliged to contend with the social and/or politic aspects of health service delivery in Northeastern Ontario.

The accounts presented in this thesis distinctly expose the inequity that exists within Northeastern Ontario's current health care delivery model. For Francophone prostate cancer patients, living within a geographically isolated social and cultural context ultimately impacted their access and experience within the system's provision of care model. Coupled with the fact that they belonged to an aging demographic with educational and cultural beliefs that do not always support proactive approaches to health care management, participants depended more on supportive others to manage their personal health care within a system that didn't allow them to understand or to be understood.

The impact of geographic-linguistic-cultural factors on the quality of life and resilience of prostate cancer patients has yet to be developed within the literature. And as such, this thesis allowed for a detailed description of an individual situation in relation to the management of their particular health care issues. The social reality in which this study occurred was broader than their experience with prostate cancer; it included a theoretical conceptualization of the manner in which participants constructed their space, their lives, their relationships and their realities in the face of their disease. More specifically, this study expanded beyond the cancer experience to uncover a deeper understanding of the overall illness trajectory and to capture their accounts of before, during and after of the illness experience.

The significance of this study was to reveal in-depth accounts of Francophone prostate cancer patients' construction and reconstruction of their realities in the face of their illness experiences and to describe behaviours and strategies they utilized. In addition, this study highlighted the need to recognize the fact that Francophone prostate cancer patients from Northeastern Ontario participants' quality of life is in peril; both because of their illness and because of the barriers they must face in terms of accessing and receiving appropriate treatments in a manner and a language they understand (and can be understood in) and can therefore act upon.

The results of this study can provide health care teams (primary and specialized care) with important information to prepare and better support future Northern patients for treatment experiences and to improve the quality of care they are currently offering for this particular group of patients. Understanding Francophone prostate cancer patients' experiences can also impact the design of treatment protocols within treatment centres by recognizing the impact of this disease and social, geographical and cultural nuances affecting these patients' access to treatment. Improved support for Northeastern Ontario Francophone patients newly diagnosed with prostate cancer and waiting to be sent to a treatment centre should be included in the referral process. In fact, the development of a transitional model of care that would support the patient between the home community and the treatment centre, and would recognize the unique circumstances these patients face in accessing care, could mitigate some of the uncertainty these men are forced to deal with by virtue of the barriers they endure. In addition, both primary physician supports and specialized treatment teams serve to gain a better understanding of patients' needs by recognizing the impact of prior health care experiences and patient preferences (including language) and concerns (including transportation) on their overall cancer experience.

Fellow researchers could also gain from the success of this research design protocol in recognizing the potential value of conducting qualitative research that is both culturally and geographically tailored for the participant pool being studied; regardless of the subject matter being studied. Although prostate cancer touches the core of men's masculine identities, this study has clearly demonstrated the appreciative value of conducting qualitative studies in a manner and method that fosters participation within men's own environments; which may

mitigate some of the recruitment challenges researchers face when dealing with sensitive subject matters by demonstrating to their potential participant pool a real desire to hear their stories, in their own words and within their own communities.

Limitations of the Study

This study was based on the in-depth interviews of twenty-two participants from eight different communities across Northeastern Ontario. The breadth of this study's sample allows for a comprehensive account of the illness experience among a population that has often been overlooked within current academic pursuits. However, given the reality of conducting research in distant communities (e.g. some communities were up to 600 kilometres away), suggested interview dates were given to participants in order to maximize the researcher's time and minimize data collection costs.

This clustered data collection process translated into a short delay in time between the initial collection and the analysis of the participant interviews. In addition, it should be noted that men who volunteered to be a part of this study could be considered to be of a particular personality predisposition (e.g. one that is compelled to participate and/or to advocate for others) that influenced their desire to share their experience. In other words, men who were either unsuccessful in their fight against the disease or those who had more complicated post-treatment experiences may have been unwilling or unable to participate in this study.

Another limitation of this study included the fact that participants provided retrospective accounts of their prostate cancer experiences. As such, relayed accounts may not have been as acute as they would have been closer to the time at diagnosis or during the ongoing treatment. However, it is my opinion that the combination of emotions, thoughts and expectations that structured the frame of each account of illness experience may have distorted the accuracy but not the veracity of each account. As such, the narratives amplified the participants' voices in reports of their illness experiences revealing their complexity and plurality. It should be noted that the systematic representation of men's prostate cancer experiences was challenging since their stories included an extremely complex set of circumstances and events, thereby increasing the risk of producing a simplistic view when interpreting their stories.

In addition, while some participants' chose to have their wives present during the interviews, this study only skims the surface of the relational dynamics that occur upon men receiving a diagnosis of prostate cancer. Further research is required to uncover the impact of this disease on the relational dynamic of couples' facing the disease and the impact of prostate cancer on a patient's broader social and familial contexts as well as the impact of delaying access to health care services because of the unavailability of these services within patients' primary language.

Future Research & Recommendations

As it has been discussed within the body of this work, recommendations for future work involve building upon the findings that have been presented within this study. In recognizing the circumstances that influenced participants' prostate cancer experiences, health care practitioners will be better suited to improve the quality and level of service they can provide, albeit within a challenged health care delivery model.

Findings from this study also suggest that programs and services (e.g. health promotion initiatives, educational sessions on treatment options and outcomes, etc.) should integrate the use of informal networks in order to provide culturally and linguistically sensitive material and delivery mechanisms for Francophone prostate cancer patients. Given most men's desire for information about prostate cancer and its available treatment options, and understanding their lack of access to primary care providers in the North, more efficient methods for the delivery of this information should be evaluated. In addition, in the case of Francophone minorities within Northeastern Ontario where English is the predominant language, identifying barriers and strategies for incorporating health-related information according to differences in language comprehension skills and functional health literacy levels is essential. Since language is recognized as a multidimensional variable, the nuances imposed by virtue of culture and/or other socio-demographic factors (e.g. age, education level, etc.) must also be considered when attempting to reach this population group with targeted prevention strategies. Health care practitioners in Northeastern Ontario should be mindful of the unique cultural and experiential contexts within Francophone populations that can inevitably influence their prostate cancer experiences.

While the reality of Northeastern Ontario's population distribution (e.g. small population counts distributed across a vast geographic catchment area) often results in difficulties accessing specialized health care services, policy makers need to be mindful of the impact that the loss of continuity of care has on both the patient and the provision of quality health care. Policy makers need to also be attentive to the local realities when developing umbrella strategies for the delivery of primary and specialized health care services for people living within our smaller, more distributed northern communities. For example, while the Northern Health Travel Grant Program helps cover travel related expenses of eligible Northern Ontario residents; this program funds travel to the "closest medical specialist or closest designated health care facility" regardless of the language of services offered at said treatment facility (Ministry of Health and Long-Term Care, 2012). As attested to throughout this study, the "closest" treatment centre may not necessarily support unilingual Francophone patients' needs and as such, would nullify their ability to access these funds causing them undue hardship as they travel even greater distances, unfinanced, in order to obtain services in French.

In addition, it is important for all parties involved in the design and implementation of programs and services to recognize that localized strategies can complement, rather than compete with, broader health programming. The challenges associated with improvements to health service delivery in the North may compete with the broader mandate of ensuring the sustainability of our publicly funded health care system, policy makers must recognize the value of incorporating both cultural and linguistic factors within its developmental framework in order to promote patients' continuity of care by accessing resources within the local-level provision of health services. Understanding Francophone prostate cancer patients' experiences is necessary in order to develop meaningful and appropriate educational, promotional and preventative interventions that recognize the influence of location, language and culture on the experiences of illness.

While much of this study focused on men's encounters, the unique insights of spouses who attended these interviews compels me to question the impact that this disease has on the spouses of those afflicted. How do spouses and partners mitigate the negative effects that prostate cancer has on the couple? What supports are available within our northern communities to support spouses and partners of prostate cancer patients? While results of this thesis have

important implications for patient care; they represent but a starting point for future research on realities of health service delivery within Northern Ontario. It is my hope that the lessons I have learned throughout the course of this academic experience will enable me to continue working on collaborative research projects that will highlight the impact of language and culture within the health care domain and spark an ongoing dialogue within health academia and community service provision initiatives. While the information contained within these pages are the product of an academic pursuit, these results belong to the brave men (and spouses) who chose to participate in this research. It is my intent to take this information back to the communities of Northeastern Ontario and hopefully, begin discussions with key stakeholders in order to bridge the gap in knowledge related to health services delivery for our Francophone populations. With our aging population, prostate cancer will continue to affect the lives of Northeastern Ontario men and their families. I wish to expand upon the framework developed within these pages in order to bring awareness to the critical nature of having access (or lack thereof) to health services in one's preferred language on the health and well-being of Francophone communities in Northeastern Ontario.

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Appendix A

Endorsement from the Honourable Jack Layton, Leader of the Official Opposition, New
Democratic Party of Canada

From: <jack.layton@parl.gc.ca>

Date: Tue, 12 Jul 2011 16:51:23 -0400

To: <kl_cote@laurentian.ca>

Subject: RE: Northern Ontario Francophone Prostate Cancer Study

Dear Kristy,

On behalf of Jack Layton, thank you for writing. Please excuse the delay in our response.

We are pleased to learn of your current thesis project on the lived experiences of Francophone Prostate Cancer Patients from Northeastern Ontario - that is fantastic!

Please find below a quote from Mr. Layton which you can use to help in the recruitment campaign. He was excited to learn of your research and sends his best wishes as you move forward with this study.

"I would like to applaud the wonderful research work which you are doing on prostate cancer. Over the years prostate cancer awareness and research has come a very long way -- owing much to you and others who continue to push for improved public awareness and better recognition of the needs of those with prostate cancer. This is essential work which helps to improve the odds for men diagnosed with this disease." - Hon. Jack Layton, Leader of the Official Opposition, New Democratic Party of Canada

Best regards,

Office of Hon. Jack Layton, P.C., M.P.

Leader of the Official Opposition

Appendix A: Bilingual Recruitment Brochure (not to scale)

Have you been diagnosed and treated for **prostate cancer** here in Northern Ontario?

Do you know someone who has?



Avez-vous été diagnostiqué et traité pour le **cancer de la prostate** ici dans le nord de l'Ontario?

Connaissez-vous quelqu'un dans cette situation?

If you are interested, or know someone who would be, please contact :

Kristy Côté, PhD Candidate
School of Rural and Northern Health
Laurentian University
Sudbury, Ontario

Toll Free 1 (855) 750-0885
✉ kl_cote@laurentian.ca

Si vous êtes intéressé, ou connaissez quelqu'un qui serait, veuillez me contacter :

Kristy Côté, candidate au doctorat
École de santé dans les milieux ruraux et du nord
Université Laurentienne
Sudbury (Ontario)

Sans frais 1 (855) 750-0885
✉ kl_cote@laurentian.ca

This research project has been approved by Laurentian University's Research Ethics Board.

Ce projet de recherche a été approuvé par le comité d'éthique de la recherche de l'Université Laurentienne.

CONVERSATION Over Coffee




Café et CONVERSATION

Sharing your Prostate Cancer Experience Can Help the Next Guy!

En partageant votre expérience avec le **cancer de la prostate**, vous pourriez aider le prochain!

Your **Story Matters** and Can Help Save Others!

Please take part in my PhD thesis research on:
"The Lived Experiences of Prostate Cancer Patients in Northeastern Ontario"



To participate, you must be:

- 18 years or above
- Diagnosed and treated for prostate cancer here in Northern Ontario
- Willing to talk about your experience with prostate cancer

As a participant, you will be asked

to take part in a confidential interview that will explore your experience being diagnosed with and treated for prostate cancer. The interview will be arranged around your schedule and at a location of your choice. You will be reimbursed for any incurred costs of participation up to \$25.

Current statistics estimate that one in seven Canadian men will develop prostate cancer during his lifetime and for one in 28, will die of it*.

An estimated 10,600 men will be diagnosed with prostate cancer in Ontario this year alone! In just one face-to-face interview, you can help other men understand that they are not alone. Your story is important and can make a difference!

- Participation is 100% voluntary
- Your name and identity will never be revealed
- Just one face-to-face interview at a time and a place that best suits you

*Source: Canadian Cancer Society, 2011

En partageant votre expérience, vous pourriez venir en aide aux autres!

SVP participez à mon projet de thèse de doctorat intitulé
« Étude qualitative du vécu des patients du nord de l'Ontario atteints de cancer de la prostate »

Pour participer, vous devez :

- Être 18 ans ou plus âgés
- Avoir été diagnostiqué et traité pour le cancer de la prostate ici dans le nord de l'Ontario
- Être voulant de parler de votre expérience avec le cancer de la prostate

En tant que participant, vous serez demandé

de participer à une entrevue confidentielle qui explorera votre expérience étant diagnostiqué et traité pour le cancer de la prostate. L'entrevue aura lieu à un temps et à un endroit de votre choix. Vous serez remboursé pour tous les coûts encourus lors de votre participation jusqu'à \$25.

Les statistiques actuelles estiment qu'un homme sur sept risque d'avoir un cancer de la prostate au cours de sa vie et un homme sur 28 en mourra*.

On estime à 10,600 le nombre d'hommes qui recevront un diagnostic de cancer de la prostate cette année! Avec seulement un entretien individuel, vous pourriez venir en aide au autres! Votre expérience compte!

- Votre participation est 100% volontaire
- Votre nom et votre identité demeureront complètement confidentiels
- Seulement une entrevue individuelle à un temps et à un endroit de votre choix

*Source : Société canadienne du cancer, 2011

Appendix B: Recruitment Posters (English/ French versions)

CONVERSATION *Over Coffee*



Participation is
100% voluntary
and **completely**
confidential.

Sharing your **Prostate Cancer** Experience Can Help the Next Guy!

Have you been diagnosed and treated for prostate cancer here in Northern Ontario?
Do you know someone who has?

**Please take part in my
PhD thesis research on:**
"The Lived Experiences of Prostate
Cancer Patients in Northern Ontario"

For more information about the study or to
participate in the study, **please contact me:**

Kristy Côté, PhD Candidate
School of Rural and Northern Health
Laurentian University
Sudbury, Ontario

 **Toll Free** 1 (855) 750-0885
 kl_cote@laurentian.ca



To participate, you must be:

- 18 years or above
- Have been diagnosed and treated for prostate cancer here in Northern Ontario
- Willing to talk about your experience with prostate cancer

As a participant, you will be asked

to take part in a confidential interview that will explore your experience being diagnosed with and treated for prostate cancer. The interview will be arranged around your schedule and at a location of your choice. You will be reimbursed for any incurred costs of participation up to \$25.

Your **Story Matters** and Can Help Save Others!

**** This research project has been approved by Laurentian University's Research Ethics Board.****

Café et CONVERSATION

Votre participation est
100% volontaire
et **complètement**
confidentielle.



En partageant **votre expérience**, vous
pourriez aider le prochain!

Avez-vous été diagnostiqué et traité pour le cancer de la prostate ici dans le nord de l'Ontario?
Connaissez-vous quelqu'un dans cette situation?

SVP participez à mon projet de thèse de doctorat intitulé

« Étude qualitative du vécu des patients du nord
de l'Ontario atteints de cancer de la prostate »

Si vous êtes intéressé ou connaissez quelqu'un
qui serait, **veuillez me contacter :**

Kristy Côté, candidate au doctorat
École de santé dans les milieux ruraux et du nord
Université Laurentienne
Sudbury (Ontario)

 **Sans frais** 1 (855) 750-0885
 kl_cote@laurentian.ca



Pour participer, vous devez :

- Être 18 ans ou plus âgés
- Avoir été diagnostiqué et traité pour le cancer de la prostate ici dans le nord de l'Ontario
- Être voulant de parler de votre expérience avec le cancer de la prostate

En tant que participant, vous serez demandé

de participer à une entrevue confidentielle qui explorera votre expérience étant diagnostiqué et traité pour le cancer de la prostate. L'entrevue aura lieu à un temps et à un endroit de votre choix. Vous serez remboursé pour tous les coûts encourus lors de votre participation jusqu'à \$25.

Vous pourriez venir en aide aux autres!

** Ce projet de recherche a été approuvé par le comité d'éthique de la recherche de l'Université Laurentienne **

Appendix C: Ethics Approval



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL	New	X	Modifications to project	Time extension
Name of Principal Investigator and school/department	Kristy Côté (Dr. Monique Benoit; supervisor) — School of Rural and Northern Health (Laurentian University)			
Title of Project	<i>A Qualitative Study of the Lived Experiences of Francophone Prostate Cancer Patients in Northeastern Ontario</i>			
REB file number	2011-04-08			
Date of original approval of project				June 2 nd 2011
Date of approval of project modifications or extension (if applicable)				
Final/Interim report due on				October 31 st 2011
Conditions placed on project	Final or Interim report on October 31 st 2011			

During the course of your research, no deviations or changes to the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please complete the appropriate [REB form](#).

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate [REB FORM](#).

In all cases, please ensure that your research complies with the [Tri-Council Policy Statement \(TCPS\)](#). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations, and best of luck in conducting your research.

Daniel Côté, Ph.D.
Chair of the *Laurentian University Research Ethics Board*
Laurentian University

Appendix D: Letters of Introduction (English/French versions)



Dear Potential Participant,

I (Kristy Côté, PhD Student Candidate, School of Rural and Northern Health, Laurentian University) invite you to take part in my PhD thesis project, 'A Qualitative Study of the Lived Experiences of Prostate Cancer Patients in Northeastern Ontario'.

This project aims to understand the nature of the prostate cancer experience of men from Northeastern Ontario in order to uncover the impact of this disease and the uncertainty it creates on men's overall quality of life. You have been asked to participate in this research because you are a Northeastern Ontario man having experienced a diagnosis of, and treatment for, prostate cancer.

The study will run from June 2011 to October 2011. Participation is voluntary and you can withdraw from the study at any time, for any reason, just by letting me know. There will be one instance for data collection. This will include one-on-one interview and a socio-demographic questionnaire. Your name and personal information will always be kept completely both during the research and afterwards. Your name and information will not appear on any documents.

The goal of this research is to learn from your experiences. Your answers about how you lived with prostate cancer will help other men who are diagnosed with the disease. This study also will help to teach health care professionals, like doctors and nurses, about the unique experiences Northeastern Ontario men face when living with prostate cancer. Also, I would be happy to share my results with you, upon request, the end of the project.

This research project has been approved by Laurentian University's Research Ethics Board.

It would be greatly appreciated if you would agree to take part in this important project.

Yours sincerely,

Kristy Côté, PhD (Candidate)
School of Rural and Northern Health
Laurentian University
(705) 561-2486
kl_cote@laurentian.ca

and

Monique Benoit, PhD
Sociology Department
Laurentian University
(705) 675-1151 ext. 4216
mbenoit@laurentian.ca

Cher participant potentiel,

Je (Kristy Côté, candidate étudiante au doctorat à l'École de santé dans les milieux ruraux et du nord à l'Université Laurentienne) vous invite à participer à mon projet de thèse de doctorat intitulé *Étude qualitative du vécu des patients du nord-est de l'Ontario atteints de cancer de la prostate*.

Cette étude consiste à explorer l'expérience des hommes du nord-est de l'Ontario qui ont ou ont eu un cancer de la prostate afin de déterminer les conséquences de cette maladie et l'incertitude qu'elle provoque quant à leur qualité de vie. Vous êtes invités à participer à cette étude parce que vous résidez dans le nord-est de l'Ontario et avez eu un cancer de la prostate et avez suivi un traitement.

L'étude se déroulera de juin 2011 à octobre 2011. Votre participation est complètement volontaire et vous pouvez cesser votre participation en tout temps simplement en m'informant de votre désir d'arrêter. Il y aura une séance de collecte de données au cours de laquelle vous aurez un entretien individuel et remplirez un questionnaire sociodémographique. Votre nom et vos renseignements personnels demeureront confidentiels tout au long de l'étude et par la suite également. Votre nom et vos renseignements personnels ne figureront sur aucun document.

Le but de cette recherche est d'apprendre de vos expériences. Vos réponses décrivant comment vous avez vécu avec le cancer de la prostate aideront d'autres hommes qui sont diagnostiqués avec cette maladie. Cette étude sera également utile pour éclairer les professionnels de la santé sur les expériences uniques des hommes du nord-est de l'Ontario atteint d'un cancer de la prostate. Si vous le désirez, vous pourrez aussi obtenir les résultats à la fin de l'étude.

Cette étude a été approuvée par le Comité d'éthique de la recherche de l'Université Laurentienne.

Nous apprécierions beaucoup que vous acceptiez de participer à cette étude importante.

Sincèrement,

Kristy Côté, candidate au Ph.D
École de santé dans les milieux ruraux et du nord
Université Laurentienne
705-561-2486
kl_cote@laurentian.ca

Monique Benoit, Ph.D.
Département de sociologie
Université Laurentienne
705-675-1151, poste 4216
mbenoit@laurentian.ca

Appendix E: Informed Consent Forms (English/French versions)



Study Title: A Qualitative Study of the Lived Experiences of Prostate Cancer Patients in Northeastern Ontario.

Principal Investigator:

Kristy Côté, PhD Student Candidate, School of Rural and Northern Health, Laurentian University

Dear potential participant,

Prostate cancer is the most common non-skin cancer in Canada with current statistics estimating that one in seven Canadian men will develop PC during his lifetime. For most men, the diagnosis and treatment for prostate cancer is a very personal experience.

This project aims to understand the nature of the prostate cancer experience of men from Northeastern Ontario in order to uncover the impact of this disease and the uncertainty it creates on men's overall quality of life. The study will help other men who are diagnosed with prostate cancer and will help educate health care professionals about the unique experiences Northeastern Ontario men face when living with prostate cancer.

The data collection for this project will include one interview and one questionnaire. After your informed consent is obtained, you will be asked to take part in one face-to-face informal interview which will take about 60-120 minutes. You will also be asked to complete a questionnaire immediately after the interview, which will take about 5-10 minutes. The unstructured and flexible format will support free-flowing conversation about any details you wish to share. Following our meeting, I will analyze the information you provided during your interview.

As a participant, you understand that:

- Participation is voluntary and that you can withdraw from the study at any time and without consequence simply by notifying the principal researcher (K. Cote).
- You agree to be audio recorded during the interview. A researcher will transcribe each interview verbatim and will label each interview by using a respondent-based coding method (ex. PA1, PA2...) in order to ensure your confidentiality and anonymity.
- Your name and location will be kept confidential throughout the project and onward. Any identifiable information will not appear on any documents.
- All information collected will be anonymized and entered into a secure database accessed only by the principal researcher. The database, reports generated by the data, consent forms, and other information collected for analysis will be securely stored in a locked cabinet in the researcher's private office behind a locked door. All electronic files will be password protected. All archive will be stored securely for a period of five years from project completion. The data will subsequently be destroyed by shredding (e.g. printed material) and through a deletion program (e.g. electronic data).

- There are two copies of this consent form. You will keep one copy and provide the signed copy to the principal researcher.

Project reports detailing the findings of the study will be generated for peer-reviewed journal publications and conference presentations.

I agree to participate in this study, and I have received a copy of this consent form.

Signature (Participant): _____ Date: _____

A copy of your interview can be made available to you.

I would like to receive a copy of my transcribed interview:

☐ Yes ☐ No

If yes, please provide your contact information:

Address: _____

Email address: _____

If you have any questions or concerns about the study or about being a subject, you may contact the principal researcher (Kristy Côté) or her supervisor (Dr. Monique Benoit, PhD) for information:

Kristy Côté, PhD Candidate
School of Rural and Northern Health
Laurentian University
(705) 561-2486
kl_cote@laurentian.ca

or Monique Benoit, PhD
Sociology Department
Laurentian University
(705) 675-1151 ext. 4216
mbenoit@laurentian.ca

This research project has been approved by Laurentian University's Research Ethics Board. For concerns or questions regarding the ethical conduct of the study, you may also contact the Laurentian University Research Officer, Dr. Jean Dragon, PhD at (705) 675-1151, ext. 3213 or email at jdragon@laurentian.ca.

Titre de l'étude: Étude qualitative du vécu des patients du nord-est de l'Ontario atteints de cancer de la prostate

Chercheuse principale:

Kristy Côté, étudiante candidate au Ph.D., École de santé dans les milieux ruraux et du nord, Université Laurentienne

Cher candidat potentiel,

Le cancer de la prostate est le cancer sous-cutané le plus commun au Canada. Les statistiques indiquent qu'un Canadien sur sept aura un cancer de la prostate au cours de sa vie. Pour la plupart des hommes, le diagnostic et le traitement pour le cancer de la prostate est une expérience très personnelle.

Ce projet vise à comprendre la nature de l'expérience de cancer de la prostate des hommes du nord-est de l'Ontario afin de découvrir l'impact de cette maladie et l'incertitude qu'il crée sur la qualité de vie des hommes. Vous êtes invité à participer à cette étude parce que vous résidez dans le nord-est de l'Ontario et avez eu un cancer de la prostate et avez suivi un traitement.

Lorsque vous aurez donné votre consentement éclairé, vous serez invité à participer à une entrevue informelle qui durera de 60 à 120 minutes, puis immédiatement après, à prendre de 5 à 10 minutes pour remplir un questionnaire. Le format non structuré et souple de l'entrevue encouragera la conversation libre sur des détails dont vous désirez parler. Ensuite, j'analyserai les informations recueillis pendant l'entrevue.

En tant que participant, vous comprenez que :

- La participation est volontaire et que vous pouvez vous retirer de l'étude en tout temps en avertissant simplement la chercheuse principale (K. Côté) et sans vous exposer à quelque conséquence que ce soit.
- Vous consentez à l'enregistrement audio de l'entrevue qui sera par la suite transcrite. La personne qui transcrira chaque entretien l'étiquettera en utilisant une méthode qui respectera la confidentialité et l'anonymat (p. ex. PA1, PA2, etc..).
- Votre nom et votre localisation demeureront confidentiels tout au long de l'étude et par la suite. Aucun renseignement permettant de vous identifier ne figurera dans les documents.
- Tous les renseignements recueillis seront dépersonnalisés et entrés dans une base de données protégée à laquelle seule la chercheuse principale. La base de données, les rapports découlant des données, les formulaires de consentement et d'autres renseignements découlant de l'analyse seront entreposés en sécurité dans un classeur fermé à clé dans le bureau privé de la chercheuse qui est aussi fermé à clé. Tous les fichiers électroniques seront protégés par un mot de passe. Toutes les archives seront entreposées en sécurité

pendant cinq ans à partir de la fin de l'étude puis seront déchetées (pour les documents imprimés) ou supprimés (pour les données électroniques).

- Ce formulaire de consentement est produit en deux exemplaires : vous en conserverez un et la chercheuse principale conservera l'autre.

Des comptes rendus détaillant les conclusions de l'étude seront produits afin d'être publiés dans des revues à comité de lecture et présentés à des conférences.

Je consens à participer à cette étude et j'ai reçu une copie de ce formulaire de consentement.

Signature (participant) : _____ Date : _____

La transcription chaque entrevue individuelle sera mise à la disposition de tous les participants.

J'aimerais recevoir la transcription de mon entrevue individuel: ☐ Oui ☐ Non

Si oui, veuillez fournir vos coordonnées:

Adresse postale : _____

Adresse électronique : _____

Si vous avez des questions ou préoccupations concernant l'étude ou le fait d'être un sujet de recherche, vous pouvez communiquer avec la chercheuse principale (Kristy Côté) ou sa superviseure (Monique Benoit, Ph.D.):

Kristy Côté, étudiante candidate au Ph.D
École de santé dans les milieux ruraux et du nord
Université Laurentienne
705-561-2486
kl_cote@laurentian.ca

et Monique Benoit, Ph.D.
Département de sociologie
Université Laurentienne
705-675-1151, poste 4216
mbenoit@laurentian.ca

Cette étude a été approuvée par le Comité d'éthique de la recherche de l'Université Laurentienne. Si vous avez des questions ou préoccupations concernant des aspects éthiques, vous pouvez aussi communiquer avec l'agent de recherche de l'Université Laurentienne, Jean Dragon, Ph.D., au 705-675-1151, poste 3213 ou à jdragon@laurentian.ca.

Appendix F: Interview Guide (English/ French versions)



NB: Please be advised that this guide is a starting point and not a final document. Consistent with the principles of grounded theory, this interview guide is prone to multiple changes during the data collection phase of this research project.

Theme 1: Prostate Cancer

1. Can you describe the events that led up to your diagnosis of prostate cancer?
2. What, if anything, did you know about prostate cancer before your diagnosis?

Theme 2: Quality of Life

1. How would you describe the person you were before your cancer diagnosis?
2. How would you describe your quality of life; both before your cancer diagnosis and now?
3. What would you say are the biggest changes [both positive and negative] that have happened in your life because of your experience with prostate cancer?

Theme 3: Services in Sudbury

1. What type of information and/or services (such as medical information, hospital services, support groups, social/family support) was available to you?
2. The Regional Cancer Program at the Sudbury Regional Hospital was developed to meet the needs of cancer patients living in Northern Ontario. In your experience, how would you evaluate the reception, information, assistance and support services provided at the Centre? Please explain your answer.

Theme 4: Francophone/Culture (FOR FRANCOPHONE RESPONDENTS ONLY)

1. Can you describe what it means to you to be a Francophone living in Northern Ontario?
2. How can the fact of being Francophone affect the quality of the services offered in cancerology?
3. In terms of services and assistance, what would you have liked to receive in your language? What would you have liked to be offered in term of services and assistance in your language?

Ending Questions:

1. After living through your experiences, what advice would you give someone who has just discovered he has prostate cancer?
2. Is there anything you think I should know to better understand your experience with prostate cancer?
3. Is there anything that you would like to ask me?

Thank you!

N.B. : Veuillez noter que ce guide est un point de départ et non pas un document final. Conformément aux principes de la théorie à base empirique, plusieurs modifications pourraient être apportées à ce guide au cours de la collecte de données pour cette étude.

Thème 1 : Cancer de la prostate

1. Pouvez-vous décrire les événements qui ont conduit au diagnostic du cancer de la prostate?
2. Que saviez-vous sur le cancer de la prostate avant le diagnostic?

Thème 2 : Qualité de vie

1. Comment décririez-vous la personne que vous étiez avant le diagnostic du cancer?
2. Comment décririez-vous votre qualité de vie avant le diagnostic et maintenant?
3. Quels sont à votre avis les plus grands changements [positifs et négatifs] qui se sont produits dans votre vie à cause de votre expérience liée au cancer de la prostate?

Thème 3 : Services à Sudbury

1. De quels types de renseignements et/ou de services (comme des renseignements médicaux, des services hospitaliers, des groupes de soutien, le soutien social et familial) disposiez-vous?
2. Le Program régional de cancérologie de l'Hôpital régional de Sudbury a été instauré afin de répondre aux besoins de patients atteints de cancer qui vivent dans le Nord de l'Ontario. D'après votre expérience, comment évaluez-vous les services de réception, d'information, d'aide et de soutien fournis au centre? Expliquez votre réponse.

Thème 4 : Francophone/Culture (POUR LES RÉPONDANTS FRANCOPHONES UNIQUEMENT)

1. Pouvez-vous décrire ce que signifie pour vous être un francophone qui vit dans le Nord de l'Ontario?
2. En quoi le fait d'être francophone peut-il influencer la qualité des services reçus en cancérologie?
3. Quels services et quelle assistance aimeriez-vous avoir reçus dans votre langue? Quels services et quelle assistance auriez-vous aimé vous voir offrir dans votre langue?

Questions de la fin :

1. Après avoir vécu ces expériences, quel conseil donneriez-vous à un homme qui vient d'apprendre qu'il a un cancer de la prostate?
2. Y a-t-il autre chose que je devrais savoir afin de mieux comprendre votre expérience touchant le cancer de la prostate?
3. Aimeriez-vous me poser des questions?

Merci!

Appendix G: Socio-Demographic Questionnaires (English/French versions)



Laurentian University
Université Laurentienne

ID# _____

PLEASE NOTE THAT THE CONTENT OF THIS QUESTIONNAIRE WILL BE USED STRICTLY FOR RESEARCH PURPOSES. ENSURE THAT THE CONSENT FORM HAS BEEN COMPLETED AND SIGNED BEFORE PROCEEDING WITH THE QUESTIONNAIRE. ALL INFORMATION WILL BE KEPT CONFIDENTIAL AND AT NO TIME WILL YOUR PERSONAL DATA BE SHARED. THANK YOU FOR YOUR TIME AND PARTICIPATION. FOR QUESTIONS, PLEASE CONTACT THE RESEARCHER AT THE TELEPHONE NUMBER PROVIDED.

PERSONAL INFORMATION

- A1.** In what country were you born? _____
If Canada, in which province? _____
- A2.** How many years have you been living in Northeastern Ontario? _____ (in years)
- A3.** What is your date of birth? _____ (month/year)
- A4.** To what ethnic or cultural group:
(e.g., English-Canadian, French-Canadian, Aboriginal [or Native], or other)
a. do you belong _____
b. does/did your father belong? _____ your mother? _____
c. does/did your spouse or partner belong? _____
- A5.** What is your current marital status:
☐ Single ☐ Married ☐ Divorced ☐ Separated
☐ Widowed ☐ Common-law
- a. How many times have you been married, or lived as married? _____
- A6.** Do you live:
☐ Alone ☐ As a couple ☐ As a family
- A7.** What is the highest year of schooling:
a. that you have completed? _____
b. that your spouse/partner has completed? _____
- A8.** What is:
a. your current employment status? _____
b. your employment status at the time of diagnosis and treatment for prostate cancer? _____
- A 8.** At the time of your last or current paid job, what was your total family income before taxes?
☐ Less than \$20,000
☐ \$20,000 - \$39,999
☐ \$40,000 - \$59,999
☐ \$60,000 - \$79,999
☐ \$80,000 - \$99,999
☐ Greater than \$100,000

HEALTH INFORMATION

- B1.** When did a doctor diagnose you with prostate cancer? _____ (year)

B2. What tests did the doctor do to diagnose the prostate cancer? (Check all that apply)

- ☐ Digital rectal examination (DRE)
- ☐ Prostate specific antigen (PROSTATE SPECIFIC ANTIGEN) blood testing
- ☐ Transrectal ultrasound examination
- ☐ Biopsy
- ☐ Others, please specify: _____
- ☐ Don't know

B4. Has this disease impacted your quality of life?

- ☐ Yes ☐ No
- ... on your finances ☐ Yes ☐ No
- ... on your family ☐ Yes ☐ No
- ... on your body ☐ Yes ☐ No
- ... on your sexuality ☐ Yes ☐ No

B5. Are there worries that you are living with because of this disease?

- ☐ Yes ☐ No

B6. What treatment did you receive for prostate cancer (e.g., surgical removal, radiation therapy, hormonal therapy, chemotherapy)?

B7. Have any members of your immediate family been diagnosed with cancer? ☐ Yes ☐ No

If Yes, Family Members:

_____ type of cancer: _____
_____ type of cancer: _____

LANGUAGE INFORMATION

C 1. What is the language that you first learned at home in childhood and can still understand? (List all that apply.) _____

C 2. What language do you speak most often at home? _____

C 3. In what languages can you conduct a conversation? (List all that apply.) _____

C 4. What is your language of preference? _____

C 5. When treated for prostate cancer, were you able to ask questions in your preferred language? ☐ Yes ☐ No

C 6. Were your questions satisfactorily answered in your preferred language?

- ☐ Yes ☐ No

F 1. Is there anything else that you would like to comment about?

F2. Would you like a copy of the study results?

- ☐ Yes ☐ No

If yes, please provide contact information where you would like the results sent:

Thank you for taking the time to complete this survey!



Questionnaire sociodémographique (version française)

N° _____

VEUILLEZ NOTER QUE LE CONTENU DE CE QUESTIONNAIRE SERVIRA UNIQUEMENT POUR LA RECHERCHE. N'oubliez pas de remplir et de signer le formulaire de consentement avant de répondre au questionnaire. Tous les renseignements demeureront confidentiels et vos données personnelles ne seront communiquées à personne. MERCI DE CONSACRER DU TEMPS À L'ÉTUDE. SI VOUS AVEZ DES QUESTIONS, APPELEZ LA CHERCHEUSE AU NUMÉRO DE TÉLÉPHONE FOURNI.

RENSEIGNEMENTS PERSONNELS

A1. Dans quel pays êtes-vous né? _____

Si vous êtes né au Canada, dans quelle province? _____

A2. Depuis combien d'années vivez-vous dans le nord-est de l'Ontario? _____

A3. Quelle est votre date de naissance? _____ (mois/année)

A4. À quel groupe ethnique ou culturel : (p. ex., Anglo-canadien, Franco-canadien, Autochtone, autre)

a. Appartenez-vous? _____

b. Appartient ou appartenait votre père? _____ votre mère? _____

c. Appartient ou appartenait votre conjointe? _____

A5. Quelle est votre situation de famille actuelle :

- ☐ Célibataire ☐ Marié ☐ Divorcé ☐ Séparé
☐ Veuf ☐ Droit commun

b. Combien de fois avez-vous été marié ou avez-vous vécu en ménage? _____

A6. Vivez-vous :

- ☐ Seul ☐ En couple ☐ En famille

A7. Quel est :

a. votre plus haut niveau de scolarisation ? _____

b. le plus niveau de scolarisation de votre conjointe? _____

A8. a. Quelle est votre situation actuelle d'emploi? _____

b. Quelle était votre situation d'emploi au moment du diagnostic et du traitement du cancer de la prostate? _____

A 9. À l'époque de votre dernier emploi rémunéré, quel était votre revenu familial total avant impôt?

- ☐ Moins de 20 000 \$
☐ 20 000 \$ - 39 999 \$
☐ 40 000 \$ - 59 999 \$
☐ 60 000 \$ - 79 999 \$
☐ 80 000 \$ - 99 999 \$
☐ Plus de 100 000 \$

RENSEIGNEMENTS SUR LA SANTÉ

B1. En quelle année avez-vous appris le diagnostic de cancer de la prostate? _____

B2. Quels examens le médecin a-t-il fait pour diagnostiquer le cancer de la prostate? (Cochez toutes les réponses pertinentes)

- ☐ Examen rectal digital
- ☐ Analyse sanguine de dépistage de l'antigène prostatique spécifique
- ☐ Échographie transrectale
- ☐ Biopsie
- ☐ Autres, précisez : _____
- ☐ Ne sait pas

B4. Cette maladie a-t-elle eu des répercussions sur votre qualité de vie?

- ☐ Oui ☐ Non
- ... sur vos finances ☐ Oui ☐ Non
- ... sur votre famille ☐ Oui ☐ Non
- ... sur votre corps ☐ Oui ☐ Non
- ... sur votre sexualité ☐ Oui ☐ Non

B5. Avez-vous des inquiétudes permanentes à cause de cette maladie?

- ☐ Oui ☐ Non

B6. Quel traitement avez-vous reçu pour le cancer de la prostate (p. ex. résection chirurgicale, radiothérapie, hormonothérapie, chimiothérapie)?

B7. Est-ce que des membres de votre famille immédiate ont aussi eu un cancer? ☐

Oui ☐ Non

Si oui, indiquez les membres de votre famille :

_____ Type de cancer : _____

_____ Type de cancer : _____

RENSEIGNEMENTS SUR LA LANGUE

C 1. Quelle est la langue ou quelles sont les langues que vous avez apprises pendant votre enfance et que vous comprenez encore? (Indiquez cette ou ces langues)

C 2. Quelle langue parlez-vous le plus souvent à la maison? _____

C 3. Dans quelle(s) langue(s) pouvez-vous tenir une conversation? (Indiquez cette ou ces langues) _____

C 4. Quelle langue préférez-vous? _____

C 5. Lors du traitement du cancer de la prostate, avez-vous pu poser des questions dans la langue que vous préférez? ☐ Oui ☐ Non

C 6. Avez-vous reçu des réponses satisfaisantes à vos questions dans la langue que vous préférez?

- ☐ Oui ☐ Non

F 1. Avez-vous des commentaires à faire sur d'autres points?

F2. Aimeriez-vous avoir les résultats de l'étude?

- ☐ Oui ☐ Non

Si oui, veuillez fournir vos coordonnées afin que nous puissions vous les transmettre :

Appendix H: Frequency Distributions of Selected Socio-Demographic Variables

I) Average Age, Average Years Since Diagnosis, Average Years in Northeastern Ontario

Selected Demographics	Average Years
Average Age	71.5
Average Years Since Diagnosis	8.6
Average Years In Northeastern Ontario	67.3

II) Marital Status

Marital Status	Percentage	Actual Number
Married	86.4%	19
Divorced	13.6%	3

III) Education Level Attained

Education	Percentage	Actual Number
Some' Elementary	22.7%	5
Elementary	27.3%	6
Some' High School	13.6%	3
High School	22.7%	5
University	9.1%	2
Graduate School	4.5%	1

IV) Reported Income Level

Gross Annual Income	Percentage	Actual Number
\$40,000 - \$59,999	40.9%	9
\$60,000 - \$79,999	36.4%	8
\$80,000 - \$99,999	9.1%	2
\$100,000 +	0.0%	0
Did Not Answer	13.6%	3

V) Treatment Modality Selected

First Line of Treatment	Percentage	Actual Number
Radical Prostatectomy	72.7%	16
Radiation Therapy	13.6%	3
Brachytherapy	4.5%	1
Hormone Therapy	9.1%	2

Appendix I: Post-Interview Report (English/ French versions)



Interview Techniques

PRIOR TO THE INTERVIEW, FIRST CONTACT

1. Present the goal of the research project
2. Explain the method of sampling
3. Ensure anonymity

DURING THE INTERVIEW

Introduce yourself

1. Define your expectations

AFTER THE INTERVIEW

1. Complete the post-interview report
 - a. Number (code) the interview
Date :
Time :
Location :
 - b. Initial contact :
Type :
Reference:
Comments:
 - c. Progression of the interview
Location:
Climate:
Strengths of the interview:
 - d. Interview content
Themes that emerged:
Themes omitted:
Privileged information:
 - e. Perceptions of the interview participant :
Body language:
Attitude:
Environment (habitat):
2. Transcribe the interview

Rapport Post-EntrevueTechniques d'entrevue**AVANT L'ENTREVUE, PREMIÈRE PRISE DE CONTACT**

1. Présenter le but de la recherche
2. Expliquer les modalités de l'échantillon
3. Assurer l'anonymat

LORS DE L'ENTREVUE

1. Se présenter
2. Définir ses attentes

APRÈS L'ENTREVUE

1. Faire le rapport post-entrevue
 - a. Numéroter l'entrevue

Date :

Heure :

Lieu :

- b. Prise de contacte :

Type :

Référence :

Commentaire :

- c. Déroulement de l'entrevue

Lieu :

Climat :

Points forts :

- d. Contenu de l'entrevue

Thèmes forts :

Thèmes oubliés :

Informations privilégiés :

- e. Perception de la personne interviewée :

Langage corporel :

Attitude :

Habitat environnement :

2. Retranscription de l'entrevue